

**THE EMOTIONAL ADJUSTMENT OF CHILDREN AND THEIR
PARENTS TO PAEDIATRIC HOSPITALISATION:
AN ASSESSMENT OF A PREPARATION APPROACH.**

**BY
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DEDICATION.

This thesis is dedicated in loving memory, to my parents , Mary Campbell MacMurchy and Finlay MacMurchy, who nurtured and loved and cared enough to set their children free to do their own exploring.

DECLARATION

I hereby declare that this thesis is my own work.

Rebecca G. Strachan
July, 1992.

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ABSTRACT.

This study reports on an investigation of the emotional adjustment of children and their parents to paediatric hospitalisation for planned ear, nose and throat surgery. The assessment of an experimental approach to preparation, which tests the efficacy of a fresh appraisal of preparation for planned surgery is presented. The cornerstone of the preparation initiative adopted for the study is that of addressing the individual needs of child and parent as they prepare to enter hospital for elective surgery. This discriminating approach to preparation is studied using combined methods. An experimental design is applied to test whether a relationship exists between the independent variable; that is, the approach to preparation for paediatric hospitalisation; and the dependent variable; that is the degree of stress and anxiety experienced by the child and his or her parent throughout the process. Combined method is applied to the present study with the aim of tapping the uniquely individual experience of child and parent at a time of heightened stress. The very rich harvest of qualitative data is analysed using the approach of discourse analysis within a hermeneutic phenomenological framework.

The theoretical framework which underpins the study is the Stress and Coping Paradigm. This model reflects the dynamic process of parent and child coping throughout the experience. The findings support the efficacy of the approach to preparation introduced by this study. Implications for the development of nursing knowledge are presented. In particular, the development of a new model which articulates the important association between maternal perceptions of control and the inter-relationship with coping mode; level of expressed anxiety; and the perceived competence of the mother in caring for her child in hospital, are put forward as an important theoretical development of the study. The value of the stress and coping paradigm as a conceptual tool with which the nurse may more fully understand the process of child and parent adjustment is put forward. Finally, the potential for the development of the role of the nurse in relation to pre-admission care, as well as implications for the way in which the nurse may assist the child and parent to maximise their coping strengths are important findings of the study.

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CHAPTER 1

1:1 INTRODUCTION.

Admission to hospital creates a series of real, imagined or potential threats for the child. Recognition of the psychological distress which accompanies hospitalisation and surgery has received much attention in the clinical and empirical literature during the past three decades.

Two fundamental assertions are made within the literature -

a) that hospitalisation and surgery are stressful, anxiety producing experiences that can cause short term and longer term emotional and behaviour problems, (Rutter, 1979; Douglas, 1975). and

b) The stress induced by hospitalisation and surgery can be mitigated by appropriate psychological preparation (Vernon, 1966; Azarnoff, 1985; Rodin, 1984).

Over the years spent in clinical nursing the writer has developed an interest and concern for the psychological well-being of the hospitalised family. Experience as a ward sister within a paediatric ear, nose and throat unit, highlighted the need to render the stress to which the children admitted are inevitably exposed, a 'controlled' experience. That is, to maximise the control the children perceive themselves to have in the situation, by appropriate preparation of child and parent for the event. Children admitted to this unit were in the writers' experience, at widely disparate levels of preparedness for the forthcoming events. Indeed, the writer recalls many instances when children were totally unprepared by their parents, who in turn, were motivated by fear of confronting the issue, or genuinely felt it better not to "upset" the child prior to his hospital admission. A previous study based within a paediatric ear, nose and throat unit (Strachan, 1988), identified parental knowledge and willingness to seek information as being linked to parental motivation to prepare the child for hospitalisation and surgery. A particular issue arising from this study was the relative lack of uptake of preparatory pre-admission ward visits, by the parents of children scheduled for hospital admission. The study concluded that one key reason for this trend was the fact that the pre-admission visit was given a low profile by the hospital personnel and was therefore made available to the better informed parents who themselves initiated arrangements for such a visit. A further issue arising from this exploratory study (Strachan 1988), was the relationship between

the level of preparation for hospitalisation and surgery and the degree of upset experienced by the child both during and after the events. The indication was that the children who were unprepared for hospital admission, did experience more immediate upset as manifest by unco-operative and aggressive or regressive behaviours both during and immediately after the events. The need for the onus to change to one of a shared responsibility, integrating the roles of the parents, professionals and managers is apparent, when we consider that the response to hospitalisation extends beyond the level of the individual child. Clinical experience supports the view expressed by Hall (1987), that there is a need to integrate the sociological and psychological perspectives that are generally considered separately.

The observation that the hospital milieu itself can be stressful to the child is accepted by health care professionals (Hall, 1987). However, acute physical needs frequently take precedence over psychological needs; medical prescription and nursing care over the child's wider psycho-social needs. The authority of doctors and nurses supersedes that of the parents, at a level which frequently challenges parental competencies and confidence at a time of heightened anxiety. This important observation, based on personal experience of the writer, during many years of clinical experience and supported by empirical data (Hall and Stacey, 1979, Hall, 1987) will be discussed in Chapter 4. During hospital admission, group life replaces the intimacy of the family relationships. Identifications are on occasions, made with the roles and activities of the staff, rather than their personal qualities. While children pass through the same stage of emotional development as they would do at home, their growth can appear distorted in two directions. One by means of the physical condition of the child and secondly by the environmental limitations which were previously accepted as part of the hospital milieu. Current attitudes and practices are challenging this assumption, as changing the environment is now considered an achievable goal, given that the attitudes of the professionals are enlightened to this aim.

1:2 Rationale for the Study.

The history of children's hospitalisation has been usefully documented by Cleary (1986). The post-war period saw a significant re-appraisal of the necessity of admitting children to hospital and concern about its psychosocial consequences. However, in spite of this new awareness, Davy, Butler and Goldstein (1972) found that by the age of seven years, 45% of British children had been hospitalised on at least one occasion. Ear, nose and Throat conditions account for a considerable percentage of childhood admissions, both in the

United States, (36%, Pruitt and Elliot, 1990) and in Britain (17-26% random sampling of five health boards). Current research into paediatric hospitalisation in North America highlights the present concern which is also felt within the United Kingdom. Namely that in the light of funding realities, the cost-effectiveness of all research undertaken must be carefully explored. Indeed our American colleagues have indicated that current research into paediatric hospitalisation is relatively sparse. (Peterson,1989). Azarnoff, (1985) warns that the preventative programmes begun in the 1970's in North America, have been discontinuing at an alarming rate. The two most commonly cited reasons for such trends have been lack of empirical validation of their effectiveness, as well as a concern about financial and temporal commitment to the programmes.

The most frequently documented method of preparation, in both paediatric hospitals and general hospitals with paediatric beds/wards, is the narrative hospital tour. (Azarnoff, 1984, Peterson, 1989). Although many children have received hospital tours, usually with accompanying question and answer sessions, very little, if any, information exists to validate the utility of this approach. Peterson, Johnston and Mullin (1984) point to a mismatch of empirical research and implementation of preparation approaches. This writer speculates that the lack of a theoretically based rationale for the effects of low cost hospital tours, have rendered it a less exciting research question, while the higher cost of equipment and other resources have made other approaches, less appealing for hospital use than the less expensive, readily available themes. It would appear that this mismatch of research and application may be very harmful to the cause of preventative preparation.

Indeed, such research may be viewed not only as cost-effective in the short term, when one considers the humane aspects of effective preparation for a stressful event, but also as *essential* if we are to avoid the longer term emotional and behaviour disorders which may arise from an uncontrolled stress in the life of a young child (Vernon; 1966, Douglas; 1975, Rutter, 1987).

1:3 The Research Questions

Clinical experience and a review of the literature during preparation for a previous pilot study, led to the identification of guiding questions. These questions, tentatively stated here, will be refined during the course of the literature review.

- 1) Will the experimental intervention, which identifies the needs of the individual child and his parents in relation to preparation for hospitalisation, influence the level of stress experienced by the child, before admission and during his stay in hospital?
- 2) Will the children who find the experience of hospitalisation and surgery a less stressful one be more likely to have been prepared for the event, within the experimental treatment condition?
- 3) Will parental expressions of satisfaction with preparation, support and care throughout the child's hospital experience, be influenced by the nature of preparation?
- 4) Will the incidence of post-admission emotional and behaviour problems be influenced by the nature of preparation for paediatric hospitalisation and surgery?

Research which investigates the efficacy of preparation approaches must address issues of empirical validation as well as the particularly topical issue of cost-effective research. A fresh approach to organising research into paediatric preparation programmes is required. One such approach, propounded by Peterson (1989), involves comparing existing techniques in order to develop the procedure having the optimum balance of efficacy and cost. The present writer is of the view that existing programmes (where indeed they do exist), are not necessarily optimum and the search for improvement in care will not progress if we evaluate on the basis of current practice alone. A rationale for this view is presented in Chapter 4.

Many of the early studies on hospitalisation have concentrated on young children, identifying the effects of separation and emotional deprivation (Bowlby 1953; Vernon and Foley 1965). Hospitalisation however, includes more than separation alone. Consideration must also be given to the effects of illness, treatments, the effects of being placed in a strange situation with multiple caretakers and living as one of a large group of similarly situated children with restrictions on behaviour. Hall, (1987) describes the effects of hospital admission as both cognitive and emotional. Children must interpret and construct a meaning for the events in which they are involved and by which their behaviour is controlled. Gellert, (1958) in a striking metaphor stated that: "To a child,

the hospital is a foreign country to whose customs, language and schedules he must learn to adapt" (p.126). How successfully children do this will depend in part on their acquired capacity for actively coping, which in turn relates closely to the child's developmental level.

1:4 Preparation for paediatric Hospitalisation - evolution of the current position.

Set into an historical perspective, the milestones in the changes in conditions under which children are hospitalised in the 1990's, lend important insights to an understanding of present philosophies. The temporal baseline from which discussions of development of psychological preparation for paediatric hospitalisation proceed, is the publication of the Report on the Welfare of Children in Hospital (Platt 1959). This report followed on from the work of Bowlby (1953), who focused on the problems of maternal/child separation ; and from the "Report on the Welfare of the Family" (WHO, 1959). The Platt report made many recommendations intended to improve awareness of and attention to, the psychosocial needs of the hospitalised child. Subsequently, the pioneering work of the Robertsons, (1970) who, in proposing a model of children's reaction to hospitalisation, overturned the then conventional paradigm which discounted distress and placed emphasis on ensuring compliance with ward routines. The 'settled' child was now to be seen, not as adapted to the situation, but as maladapted. An awareness of the significance of withdrawal as an indication of extreme distress reaction by the child was therefore put forward (Robertson, 1970). This important observation will be discussed in Chapter 3.

In the same way that children's behaviour was reassessed, so too was the status of parents. The National Association for the Welfare of Children in Hospital (NAWCH), which was set up in the wake of the Platt Report, continues to campaign vigorously for unrestricted visiting rights, adequate rooming-in facilities for parents of sick children and for the care of all sick children to be delivered by Registered Sick Childrens Nurses within a paediatric hospital. Thornes (1986) argues that we are still a long way off full implementation of Platt. In some areas parents are seen as close and necessary partners in their child's care, while in other situations parents are still perceived as visitors and subjected to restrictive access to their sick child. This latter phenomenon is found more frequently where children are nursed in non-paediatric hospitals. Stenbak (1986) in his review of child care practices across Europe, found that ear, nose and throat wards in particular, still present many obstacles to open visiting policy, particularly on operating day.

Robinson (1987), suggests that the relationship between knowledge and action lends insight into the reasons for failure of full implementation of the Platt recommendations. The dichotomy between the way in which knowledge is perceived and the way in which it is applied has been explored in the study by Hall and Stacey (1979), who, in their search for factors 'beyond separation' causing distress to the child, report that " The organisational aspects of hospitals are as important for understanding individual disturbance as are the insights into psychology"(p.8). The authors go on to suggest that the resistance to change in hospitals is not a separate problem, but in part at least a further aspect of the original problem, given that a system of relationships opposed to change may be related to that causing the distress to children. Regrettably, the research evidence suggests that there are still many improvements to be made in the way in which children are prepared for and experience, care in hospital. It appears that knowledge is a necessary but insufficient condition for effecting change.

Many of the previous studies have depended on the researcher implementing new approaches to preparation. The value of extending the role of the nurse in relation to preparation for hospitalisation is apparent when we consider the benefit of active involvement in child and family care and the subsequent improvement in health care delivery during the period of in- hospital care. This study intends that implementation of the experimental intervention will be carried out by the staff normally responsible for child and family care. As will be discussed in chapter 6, this approach is preferred since it increases the potential and likelihood of implementation of preparation programmes following the study, should the experimental intervention prove an effective approach to preparation. Also direct participation by the ward staff normally responsible for child and family care is expected to increase the motivation and satisfaction experienced by the nursing staff. It is important in a study of this nature to examine not only the complex array of factors which determine child and parental responses, but also the perspectives of the staff responsible for health care within the setting studied. It may be speculated that, in addition to the reasons cited by our North American colleagues for failure of preparation programmes, namely limitations of financial and other resources, that the staff responsible for implementing such programmes were research staff who, following collection of the data withdrew from the clinical area, may well explain in part, the failure of continuation of effective preparation of children.

1:5 Outline of Chapters 2-12

Chapter 2 is concerned with the first section of the literature review. The focus on stress and coping is considered to be justified in terms of the nature of the experience when

children enter the health care setting. The impact of events on parents require to be studied in the context of parental role and an understanding of the anxieties which parents have as they admit their child to hospital for surgical treatments.

Chapter 3. will address the key individual differences which are to be considered in a study which sets out to examine the responses of children to stress in the medical setting. In addition, a focus on developmental concerns highlights the importance of viewing children's responses against a rapidly changing pattern of development. For example, maternal-child attachment in the medical setting is addressed in terms of the developmental differences in attachment behaviour, as well as in relation to child and parent expectations. The important issues of vulnerability and resilience will then be reviewed in relation to identification of those factors which are thought to render the child more or less vulnerable to the effects of stress during health care treatments. Finally, chapter 3 will briefly review children's conceptions of illness and medical treatments in relation to the developmental norm. This is considered to be important in relation to an interpretation of the responses children make which in turn may lead to an awareness of the personal meaning of the events for children at varying stages of development.

Chapter 4. is concerned with a review of the literature which focuses on the child in hospital. Preparation for paediatric hospitalisation will be addressed. This will encompass parental as well as child preparation initiatives. Approaches to preparation both within Britain and in North America will be discussed. This cross cultural comparison is especially useful in the light of the current changes facing health care provision in Britain, changes which Canadian and American colleagues have observed in the past five years. Chapter 4 will then examine the role of the nurse in relation to preparation for paediatric hospitalisation. Finally, the theoretical framework which was informed by the literature review and underpins the present study, will then be described.

Chapters 5, 6 and 7 are concerned with methodological considerations and a discussion of instruments and measurement techniques applicable to the present study.

Chapter 8 focuses on the setting and also explores the ethical issues related to data collection within a Sick Children's Hospital.

Chapter 9 is concerned with the presentation of the findings from the quantitative analysis. Chapters 10 and 11 focus on an interpretive analysis of child and parent

responses throughout the experience.

Finally, chapter 12 concludes with an integrative discussion of the analyses and the implications and recommendations arising from the study.

Review of the literature identified as being central to an understanding of the issues under discussion is now presented.

CHAPTER 2

REVIEW OF THE STRESS RELATED LITERATURE.

Introduction.

In the early stages of this study, during which I considered the topic of my research, I was influenced by my prior knowledge of the literature, reviewed during a previous small study (Strachan, 1988). In addition, the impact of my previous clinical experience in paediatric nursing and in nurse teaching focused attention on the responses of children and their parents to the events which comprise a child's admission to hospital and subsequent treatments.

2:1 Approach to the Literature Review.

This review was conducted in two major stages. The first stage used the 'key word' search and thus identified the central areas included when studying the experiences of 'Children in Hospital'. The theoretical orientation suggested by the early stages of the review was that of a stress and coping paradigm to inform the discussions of children in hospital.

The second phase of the review was conducted against this stress and coping framework and addressed the nature of coping in children before turning to the coping responses of the hospitalised child. This in turn led to a refined review which subsequently led to an examination of individual differences in response to stress. In particular the need for a developmental framework to inform an understanding of children's responses in the medical setting was considered to be important in the light of past clinical and teaching experience of the writer. The role of other individual differences as they impinge on the responses of the child to hospitalisation and surgery will also be reviewed. These include a discussion on children's conceptions of illness and medical treatments, as well as a review of differences in vulnerability to these experiences.

Attention then focused on preparation for the stressful event. That this preparation should include the parents, (an issue not addressed by the majority of the literature reviewed) as well as the child, is put forward in this study as an essential pre-requisite to meeting the needs of the hospitalised family. Review of the adult-coping literature and discussion of parental anxiety will therefore be presented briefly, with the aim of further

informing an understanding of parental coping.

This selective review of the prolific literature which attends paediatric hospitalisation is presented with reference to the changes in practice which have taken place over time. That is; the pre- 1965 literature is referred to in relation to the impact of the findings from earlier studies on subsequent writings. It is important at the outset to identify the salient factors which reflect how policies and practices have changed. A striking example of this is the sharp contrast between parental rights, particularly in relation to the limited access to the sick child, in the 1960's and early 1970's and the comparatively open policies which now prevail. Further developments include those which relate directly to the way in which nursing is practiced. For example the evolution of nursing practice which now addresses *nursing* paradigms upon which family care is based, reflects a major shift from the previous unquestioning acceptance of the medical model of patient care.

In drawing together the literature relevant to the present study, a degree of overlap is inevitable within the theoretical positions reviewed. However, it is expected that this will serve to underline the complexity of the issues arising and the multi-disciplinary approach necessary to effect intervention.

In order to do justice to the wide range of theoretical and practical issues raised by this study, it was important to consider knowledge in a number of disciplines. These include psychology, nursing, developmental paediatrics, psychiatry and sociology. In the pursuit of clarity, and for the purpose of logical development of the review, the literature will be presented in the following way:

2:2 Structure of the Review

Review of the literature will be divided into three distinct but mutually complementary sections. The first section presents the literature on **stress and coping** and will be further sub-divided to concentrate on major identified themes.

- i) Approaches to stress research
- ii) Stress and Coping, a conceptual framework
- iii) Children's Coping
- iv) Coping in the Hospitalised Child

The above issues command a prolific and diverse literature. The present review will be limited to an exploration of the concepts as they relate directly to the present study.

Section two addresses the **individual differences** of specific concern to this study and will

be further sub-divided:

- i) Developmental Concerns
- ii) Children's Conceptions of illness and Medical Treatment
- iii) Issues of Vulnerability and Resilience.

Consideration will then be given to **preparation for paediatric hospital admission**. This will address the needs of the parents as well as those of the child in relation to preparation for a stressful encounter.

Section three will therefore comprise:

- i). The nature of stress when a Child is Hospitalised
- ii). Preparing Children for Hospital
- iii) Preparation of the Parents
- iv). The role of the Nurse

2 : 3 The Stress Related Literature

Stress: Introduction and classification

There are few areas of contemporary health care and psychology that receive more attention than stress. Reviewing the major perspectives concerning stress is presented with the goal of clarifying the nature of what has proved to be a heuristic but vague construct. The prolific literature reflects the widely-held belief that stress is a major factor affecting people's lives, is intimately linked with mental health, and is increasingly the focus of interest in relation to the aetiology of physical health disorders. (Kaplan, 1983; Lazarus and Folkman, 1984-a; Hobfall, 1989). The study of stress is directly applicable to the problems of everyday life and offers a route to understanding if not eliminating the conceptual problems. The practical application of stress as a concept in research initiatives is met with an important caveat as McGrath (1970) succinctly states:

... Systematic basic research is viewed as the more fruitful route to scientific knowledge which is both sound and applicable to real-life situations and problems. It is necessary to explore the methodological, conceptual and substantive issues which are central to stress research and which are therefore preconditions to advancing knowledge of human stress and its effects. (p 23).

McGrath (1970) further states: "Our facts must be correct, our theories need not be so, as long as they are useful in generating new facts" (p.12).

Stress, although a term used by lay and research persons alike, is, in Garmezy and Rutter's'

(1983) view, a much misunderstood term. Indeed, Seyle (1980), the father of modern stress research suggests: "Like relativity, stress is a scientific concept which has suffered from the mixed blessing of being too well known and too little understood" (p.27). Researchers have, on the whole, considerable difficulty defining stress, preferring instead to refer to the concepts subsumed within the stress paradigm, for example, anxiety, frustration and emotional disturbance. Therefore, the term 'stress' appears to pre-empt a field shared by other negative concepts. Miller (1960), reminds us that the discipline of the philosophy of science "Craves wary walking in the thicket of ill-defined concepts" (p34).

Indeed, Rutter (1982) comments there is no doubt that stress constitutes just such a thicket, with an unusually rich growth of tangled thoughts and thorny assumptions. (p 11) In a more direct critique, Adler (1980) comments:

... there is little heuristic value in the concept of stress. It has come to be used as an explanation of altered psycho-physiological states ... the inclusive label 'stress' contributes little to an analysis of the mechanisms that underline or determine the organisms' responses and further may impede conceptual and empirical advances by fostering the reductionist search for simple mono-cause explorations. (p 312)

In directly addressing this vociferous critique, attention requires to be given to the 'definitional' issues which attend the use of the concept. Attempt to define stress, although an apparently contradictory goal, is used in the context of this study as an attempt to focus on and collate the many conceptualisations offered. The use of stress as a descriptive, rather than an explanatory concept, has many clinical and empirical advantages. Despite over-inclusiveness and global use, the stress concept draws attention to important phenomena. It is essential for researchers using stress as an organising concept to adopt a systematic theoretical framework for examining the concept at differing levels of analysis. A pre-requisite to this aim is to attempt a definition of stress with greater precision before it can become a viable tool in research initiatives. As a preliminary to this goal, a brief discussion of the historical perspectives on stress is presented to lend an insight into the evolution of current paradigms.

Stress: An historical perspective

The Oxford English dictionary states that the use of the term 'stress' can be pre-dated to at least the early 14th century, at which time the word had already acquired several opposing meanings, mainly to denote hardship, adversity or affliction.

In the early 19th century, Osler, a physician with an interest in psychiatry, described the concepts of stress and strain as the basis for ill-health. In presenting this hypothesis, Osler postulated an association between personality traits and susceptibility to dis-ease.

(This theme is currently the subject of much debate, articulated as the psychobiological approach to health and illness, Steptoe, 1990). Canon (1933-39) considered stress a disturbance of homeostasis under adverse environmental and physiological conditions. Exposure to extremes of body temperature, low levels of circulating blood sugar and relative lack of oxygen were the key examples Canon cited for his disequilibrium hypothesis. This, in fact, is the first documented potential *measure* of stress, although Canon did not progress to presenting scientific measures of the phenomena he described.

Canon's emphasis on stress as response was extended and developed by Hans Selye. Selye (1950 - 1956) used the term 'stress' in a technically precise way to describe an orchestrated set of bodily defences against any noxious stimuli. The central tenet of Selye's early conceptualization of stress was that of a universal set of physiological reactions and processes created by the demands of an altered bodily state. This Selye collectively termed the General Adaptation Syndrome (GAS). Although clearly a physiological orientation, concerned centrally with hormonal responses during periods of stress, Selye, influenced by the growth of cognitive psychology, did, in later writings, indirectly address the psychological components of stress. (Selye 1980).

McGrath (1970), commenting on the popularity of stress research, points out that there is often a theoretical and methodological history leading up to the point where a research topic 'blossoms'. The history of stress research exemplifies this point. It becomes clear on reviewing the literature that stress theories, in keeping with other theoretical formulations evolved over time, have reached their present state of understanding as a result of an accumulation and integration of differing perspectives. A brief resumé of these perspectives is now presented. It is relevant, however, to note that it is specifically not the intention to present an exhaustive or comprehensive review of stress theories, but rather to highlight the central approaches mentioned prior to selection of an appropriate paradigm which informs and underpins the present research.

2 : 4 Approaches to stress research

The *Zeitgeist*, described by McGrath (1970) as both conceptual and practical, is evident when the stress-related literature spanning the past five decades is reviewed. The publication, in 1958, of the study by Janis exploring surgical threat in a patient undergoing treatment, was one basis for the popularisation of the term 'stress' and subsequently led to an increased concern with the social and environmental sources of stress. The publication of the Platt report, on the Welfare of Children in Hospital (1959), identified environmental factors within the hospital milieu as being significant in an aetiology of stress in hospitalised children. This significant report has served as a catalyst in the area of the psychosocial needs of the hospitalised child.

Seyle's (1956) approach to stress as a non-specific response of the body to any demand may be challenged by the view that *every* demand made on the body is specific - *and is unique*. Stressors, for example, heat, cold, joy, hormone activity, emotional trauma, all have a common factor, that is they increase the body's demand for re-adjustment. This involves mobilising adaptive functions which will re-establish normal equilibrium. Seyle argues that the non-specific adaptive response of the body is consistent, regardless of the stimulus; what varies is the degree of response. This, in Seyle's view, depends solely on the intensity of the demand for adjustment. Within this framework, it is immaterial whether the stressor is negative or positive, since the systematic reaction produced is the same. The *effects* of the reaction, however, may be diverse. By definition, Seyle's view of stress states that it cannot be avoided since it pervades every aspect of daily living. In practical terms, a distinction is made between eustress and distress. The former refers to pleasant or non-harmful stress, while the latter describes stress as is widely viewed - causing disequilibrium and 'dis-ease'.

Hobfall (1989) asserts that Seyle's conceptualization's of stress may be further criticised for employing illogical deductive reasoning. This critique is made with reference to Seyle's description of stress in terms of outcome, in the sense that an organism could be seen as under stress only when a phase of the 'general adaptation' sequence was occurring. This viewpoint belies the possibility of prospectively identifying the cause of stress prior to the outcome.

In criticising earlier formulations on stress theories, it is important to remain mindful of the psycho-social climate which prevailed at the time. That is, the presence of stress being dependent on the observed manifestations of a stressful state is indicative of the absence of an awareness of the complexity of stress and coping in context. In later writings, Seyle (1980) did accept the influence of the person interacting with the environment in shaping response to stress. There are examples, also, of writers who appeared to be 'ahead of their time' in their understanding of the stress concept, for example, Cannon (1933) and Spitz (1949). The latter author presented a clinicians view of stress-related experiences of children in institutions. Much of this early work is currently being extended and applied to present-day paediatric practices.

Within the stimulus definitions of stress, the concept is identified according to the nature of the stimulus, rather than the response. Events are therefore considered stressful on the basis of whether they normally lead to stress reactions, such as emotional upset, psychological distress or physical impediments. The stimulus is thereby a stressor. Lindemann (1944) and Caplan (1964) were among the first to introduce a psychological

view of stress as opposed to the physiological position adopted by Seyle. This psychological stance also challenged the psychoanalytic view of stress; that is, psychological stress was *not* invariably the sequelae of deep-seated personality disturbance, but rather the product of personal confrontation with stressful events.

The significance of this early work is based on the focus of critical life events and extreme challenges to the individual self or social world (Caplan, 1964). The studies on bereavement (Parkes, 1972), which view stress or change which requires adaptation may be seen as a development of this theoretical position.

The stress concept - a current position

Concern with individual differences grew out of research on the effects of stress on performance. A proliferation of laboratory-based studies, testing the simplistic view that stress or anxiety resulted in impairment of performance, led to the recognition of important individual differences. This development challenged the assumption that prediction of performance could be made by reference solely to stressful stimuli.

McGrath (1970) purports that the stress concept holds much promise as an integrating concept. He goes on to suggest that some fundamental connections among neighbouring but isolated fields may be made, in particular, physiology, psychology, medicine and sociology. This attempt at integration is represented par-excellence in the psychobiological stress response theories of Steptoe (1980), and also in the emotional and behaviour process approach suggested by Leventhal (1989). The latter author sets out an elaborate framework for the analysis of behavioural process within a medical setting. The aim of this framework is the integration of diverse views which arise when behaviour is viewed through the separate conceptual windows of sociology, psychology and physiology. Leventhal extends his framework to suggest how concepts at one level may be 'connected or nested within those of another' (p.56).

A growing consideration of psychological factors as they relate to health and health-care is apparent. Revival of interest in the psychosomatic perspective, which, in turn, is prompted by a recent change in outlook in relation to stress and illness (Cohen and Lazarus, 1979; and Brown, 1975) is observed. Current psychosomatic thought is heavily embedded in stress-theory encouraged by the interdisciplinary approach referred to above.

Currently, the stress concept holds that psychological stress is viewed as a general outcome for different though related processes of person-environment transactions in which demands tax, or exceed the resources and the individual (Coyne, Aldwin and Lazarus, 1981).

2:5 Issues of definition

Having briefly reviewed a classification and approaches to stress research, clarification of the concept under discussion is presented. The caveat which attends definition of the stress concept has been addressed (p14) It is accepted that the current position has clearly evolved from past conceptualisations as well as present empirical findings. Definitions of stress generally refer to a variety of phenomena, some of which transcend the individual as the unit of analysis. Examples are: ecosystem stress, economic and social stress. The focus of interest of the present review, however, is on stress as it relates to individuals. While cognizant of the interplay between factors which constitute stress, and of the very wide variability in its individual appraisal, a definition is essential to focus attention on the issues arising and to subsequently render operational definition of the concepts studied, a possibility in empirical research.

An eclectic approach to definition, while all-embracing, does little to enhance the pursuit of clarity. Categories of definition have hitherto been centred on stimulus-based definitions, intervening process definition, response-based, and, more recently, on resources and their enhancement. In addition, divisive approaches relate the positivist position to stress definition as being either stimulus or response, but ignoring individual differences. On the one hand, the phenomenological approach to conceptualising stress which emphasises the relationship between the person and the environment has been criticised as being 'too phenomenological' (Hobfall, 1989). While other approaches are criticised for not adequately addressing the individual in the stress equation (for example, Seyle, 1981). A balance requires to be achieved between the overly phenomenological and the deterministic focus on stress. A theory should be useful in generating new facts as well as in the conceptualisation of the area under investigation. It is important therefore that a 'working definition' of the construct is a viable goal.

There is general agreement that stress is a condition or situation that imposes demands for adjustment on the part of the individual (Goldensen, 1973). It is an experience causing disequilibrium with the potential for either a positive or negative resolution. It is evident from an extensive review of the literature that no issue in the psychology of health is of greater interest and importance than whether (and how) stress influences adaptational outcomes such as emotional well-being, social functioning and somatic health (Auerbach, 1989 ; Johnston and Wallace, 1990). The importance of the relationship between stress and health also helps to account for the continued interest in the theory of stress and coping explored in recent years by Lazarus (Lazarus and Folkman, 1984-a). In this theory, psychological stress refers to: "A relationship with the environment that the person

appraises as significant for his or her well-being and in which the demands tax or exceed available coping resources " (p.21). Lazarus' conceptualisation of stress is particularly relevant to studies within health care settings and is applied to this study. Therefore the definition adopted by the study will be that of Lazarus and his colleagues (1984-a).

Lazarus goes on to suggest that no environmental event can reasonably be identified as a stressor independently of its *appraised significance to the person*, even when an event is judged to be stressful. However, Lazarus also contends that to speak of a stressor in an objective and normative sense is to ignore the inevitable and extensive individual differences in response to similar environmental conditions. The two key areas of Lazarus' model which address the unique nature of the hospitalisation experience, that is the issue of personal meaning and of individual differences in response to stress, also appear to contradict the fundamental premise on which this study is based, that is that hospitalisation is a stressful experience for children and their families. However, the pivotal dimension of the stress and coping paradigm of Lazarus also emphasises the *relationship* between the unique characteristics of the person on the one hand and the nature of the environment on the other. Many previous studies have emphasised the role of the environment in determining children's responses to hospital (Hall and Stacey, 1979, Hall, 1987), while failing to adequately address the individual in the context of the environment. Conversely a few studies have placed the emphasis on factors within the individual in shaping his responses to the stressful encounter (LaMontagne, 1987). The present study will seek to address the essential relationship between the factors which operate within the individual and those which arise from within the environment. The theoretical framework of the present study can more appropriately be discussed fully at the end of this review.

In asking the question 'Is psychological stress rubric or variable?', Lazarus (1984-a) goes on to argue that stress is best regarded as a complex rubric, more akin to emotion, motivation or cognition, rather than as a simple variable. The meaning sphere of stress is explained by many variables and processes that are reflected in the persons appraisal of a relationship with the environment, particularly when influencing well-being and taxing personal and situation resources. Within the multi-variate, multi-process system proposed by Lazarus and his colleagues, it is clear that no single variable, whether in the environment or within the person, whether a process or an outcome, can *alone* represent stress. All the variables within the system can contribute to the immediate appraisal of stress and its emotional effects. Also, the likelihood of longer-term effects is more of a risk if a given process is stable or recurrent over time or across encounters (Lazarus and Folkman, 1984-b). This position, however, belies the potential 'steeling' effect of stress described by

Rutter (1985) and is of particular importance in the field of health-care, where 'successful' coping is not necessarily contingent upon successful outcome of the health-care received (Cousins, 1976).

The idea of stress as a rubric rather than a variable can be more readily understood if the system as a whole is considered. A situation is thereby reached where Adler's (1980) position may be confronted and stress may be viewed as a convenient term with much heuristic value. When stress is used to relate to the operation of many variables and processes when demands tax or exceed the individual's resources, the individual appraises the encounter as relevant to well-being and subsequently engages in coping processes and responds cognitively, affectively, or behaviourally (Lazarus, 1984).

The conceptualisations of Lazarus and colleagues have not gone unchallenged. The most succinct critique describes Lazarus' paradigm as overly phenomenological and ambiguous, and consequently not amenable to empirical testing (Hobfall, 1989). Stress researchers are frequently criticised for avoiding the problem of definition, choosing instead to study stress without reference to a clear framework. In refuting the critique of Hobfall (1986), Lazarus addresses the definitional issues and presents a clear, unambiguous theoretical framework based on his cognitive, phenomenological transactional model of stress. Fragmentation of aspects of a theory does little in the long-term to foster the integrative perspective required when stress as an organising concept is used in health-care and other settings.

Definitions of stress are as prolific as the documented attempts to place stress within a theoretically-grounded framework. Paediatric literature refers to two broad types of stress, situational and developmental, generally relating chronological age to developmental stress (Petrillo and Sanger, 1980; and Poster, 1989). Situational stress is generally defined in terms of life events perceived as threatening (Holmes and Rahe, 1967; and Yamamoto, 1987). It is evident that the two broad categories occur simultaneously in many instances, that is, a child in the process of pre-operational cognitive development may also be admitted to hospital for medical treatment. Kagan (1983), in proposing a developmental model, asserts that stress must be viewed as an interaction between want and response. Kagan emphasises that stress will not be adequately understood if either of those factors are studied in isolation from the other. While addressing the reciprocal relationship between person and environment, that is, compatible with the transactional model of, for example, Lazarus, Kagan describes an approach to stress which is essentially deficit-based. Stress in Kagan's view, arises because of deficits in the environment, within the child or in their interactions. This is a reductionist perspective which fails to address the wide range of potential stressors, and the considerable repertoire of coping-behaviours

available to children at specific stages of cognitive development.

Other writers view stress as a meta-concept (Bailey and Clarke, 1989) in drawing together the disparate phenomena which is stress. The cognitive, phenomenological transactional view of stress and coping perceives the individual as a dynamic system attempting to control levels of threat or demand to which he or she is exposed by effective coping. The process of coping, which is reviewed in a later section, is situationally and person specific. Coping as a process is a multi-faceted evolving dynamic state.

Antonovsky (1979), in his controversial treatise on stress, succinctly encapsulates the essence of day-to-day stress:

... History and the immediate world around us supply us with a considerable panorama of stressors. I suggest without ignoring this panorama that the daily social structures in which we are all embedded are inevitable and perpetually stressful. (p 44)

Antonovsky goes on to suggest that recognition of the paradigm of a total normal life-cycle, at the core of which lies an 'endless series of challenges' has only recently been addressed by developmental psychology. What makes these endless series of challenges normative or possible to assimilate within the normal range of human adaptive resources is the ability to cope effectively with the vast array of challenge or threat.

Hobfall (1989), in attempting to remedy the shortcomings of previous theoretical positions, presents his 'conservation of resources' model. Within this model, an attempt is made to bridge the gap between environmental and cognitive viewpoints of stress. The basic tenet of the conservation of resources model is that people strive to retain, protect and build resources and that what is threatening to them is the actual or potential loss of such valued resources. Examples of such resources include mastery (Kanner, 1981), self-esteem (Rosenberg, 1965), learned resourcefulness (Rosenbaum and Sonira, 1986) and socio-economic status (Parry, 1986.) The view that the individual will actively seek to create a world that will provide harmony and success is a long-standing one in psychology. Pearlin, Lieberman and Mullen (1981) have similarly proposed that: "The protection and enhancement of self... are fundamental goals after which people strive" (p.340). This is important in relation to the child in hospital, as children are seen to actively strive to hold onto a degree of autonomy and dignity. This aim is facilitated by the presence of adequate support, which in the case of a child, is generally the parent.

The goal of maximising positive reinforcement is central to social learning theory, from which Hobfall's model is, in part, derived. Hobfall views stress as a reaction to the

environment in which there is either the threat of a net loss of resources or the actual loss of resources or the lack of resource gain following the investment of resources. Therefore, both perceived and actual loss, or lack of gain, are considered potential producers of stress. Two major issues arise from Hobfall's conceptualisations. The first is that the author implicitly considers 'resource gain' to be central to any encounter with stress which mobilises personal resources. The author does not specify the character or nature of resource gain but simply states the range of resources available to the individual. This includes personal as well as situation characteristics explicated by Lazarus (1980;1984-b) and his colleagues. In addition, Hobfall's model, in attempting a new conceptualisation of stress, in fact isolates resources as the single significant unit, not only in comprehending stress but also in the individual's ability to effect coping.

A further point of critique is the assumption that the individual has adequate resources initially, or indeed can mobilise them in a stressful encounter. Studies of coping during acute crises (for example, Garmezy, 1981) indicate that this is not necessarily the case. In essence, Hobfall's critique of other theorists, while leading to an interesting debate on resources, offers no new ground and, more significantly, is less well theoretically grounded than the model it purports to supersede, that of a cognitive transactional approach.

There is no general consensus on a clear definition of stress. However, without a clear theoretical backdrop, it is difficult to create a true body of knowledge because there are no defined borders of theory to challenge (Kasl, 1978). Mindful of the truism of Kurt Lewin, 'There is nothing as practical as a good theory', the importance of applying the stress-model to the research conducted is a key concern. The present study addressed these limitations and adopts the position that no single theory can effectively communicate the many complex areas to be addressed when children and their parents cope with the stress of hospital admission. However, the framework of Lazarus and Folkman (1984-a), presents a clear framework for the study of stress in the medical setting, and will be operationalised in a later section.

2:6 Stress appraisal and coping - a conceptual framework

Having sharpened the focus of the global term 'stress' and retained its use as an organising and descriptive concept, a more discriminating analysis of the contrasting types of life events considered to be stressful require to be studied.

As a preliminary to that aim, it is necessary to consider the different ways in which people respond to or cope with stress events or situations. By focusing on the nature of the stimuli that provoke response, rather than solely on the responses themselves, an

integrative perspective on stress is possible. Most writers place the key emphasis on psychological variables as the pre-potent stimulators of the response to stress. Therefore, it is not just the stimuli, or the physical environment *per se* that determines the physical response but the individual's evaluation of these stimuli (Levine and Weinberg, 1978). Most forms of psycho-social stress do not constitute a short term single stimulus, but rather a complex set of changing conditions that have a history and a future (Mechanic, 1978). Coping therefore requires to be considered as a process extending over time. This process is seen as the key to an understanding of stress reactions.

The Oxford English dictionary defines 'cope' as to prove a match for, contend successfully with, to match in the sense of a conflict, or to deal competently with a problem.

Implicit in the above definitions is the presence of personal activity, deliberateness, and successful outcome. In current psychological literature, the term 'coping' refers to specific behavioural or cognitive actions that are used to respond to a problem.

In addressing the conceptual and definitional issues which attend 'coping', Lazarus and Folkman (1984) challenge the traditional trait-oriented approach in four main areas.

First, the transactional phenomenological approach is a process-oriented approach, while the trait views consider coping as a fixed static characteristic. The second point is that Lazarus' definition limits coping to conditions of psychological stress which require mobilisation of effort. This specifically excludes theories of coping which consider automatic behaviour and thought. Third, Lazarus also attends to the problem of confounding coping with outcome:

"When efficacy is implied by coping and inefficacy by defence, there is an inevitable confounding between the process of coping and the outcome of coping"(p.133).

By defining 'coping' as *effort* to manage which includes within the coping context *anything* that the individual does or thinks, without reference to whether it is successful or not, Lazarus is directly addressing the effort component of coping. It is apparent that in clinical research as well as in other stressful situations, the study of the coping process is enhanced by maintaining a distance between the coping process and coping outcomes.

The fourth point addressed the use of the term 'manage' in that coping is not equated with mastery. Managing can include degrees of adjustment, for example, minimising, tolerating or accepting stressful situations. Tunks and Bellissimo (1988) comment that specific coping strategies are not inherently adaptive or maladaptive. The authors favour instead the situation specificity of such strategies. Also, skills that may be beneficial and adequate in one situation, may be inadequate or positively harmful if relied upon exclusively. For example, the child who is the victim of playground teasing/bullying may learn to respond

with aggression to the point where self-sufficiency ensures continued self-esteem. However, this same child in a hospital ward may perceive the situation as similarly threatening but to respond with hostility is likely to mask his vulnerability to the threat imposed by the unfamiliar environment. The sensitivity of the professionals is called upon to ensure his autonomy in this situation. The use of term 'skill' in relation to coping highlights the positive aspects that may be taught and used flexibly as the situation requires. This is the basis of many coping skills programmes used as preparation initiatives in health care settings.

Lazarus and Launier (1978) , suggest that:

... the ways people cope with stress may be even more important to overall morale, social functioning and health/illness than the frequency and severity of the stress episodes themselves. (p 308)

and they define coping as:

... constantly changing cognitive and behavioural efforts both action oriented and intrapsychic to manage environmental and internal demands and conflicts among them, which tax or exceed a person's resources (p.178).

By 'managing' demands, Lazarus includes a wide range of coping behaviour making no hierarchical judgements about their efficacy; that is, to master, tolerate, reduce or minimise are included within the 'management' of demands. Resources and steps taken to utilise them in managing stress, while clearly of importance, require to be considered as part of the broader issue of individual differences.

Lazarus et al (1984-a) reminds us that it is the essence of human nature to differ in vulnerability to certain types of events as well as in their interpretations and reactions to them. Similarly, Garmezy and Rutter (1983), while preferring to focus on the positive issue of resilience, cite many examples of individual variations in response to stressors. Since the early 1960s, Lazarus and his colleagues have applied the concept of cognitive appraisal to the individual's judgements about demands and constraints in ongoing transactions with the environment and his or her resources and options for managing them. A central tenet of this theory is that these judgements are continually re-evaluated. As coping is central to the individual's adjustment to the stress of illness and hospitalisation, nursing practice involves implicit assessment of the child or adult patients' coping processes as they unfold across the course of the stressful experience.

A main thrust of current coping theory is grounded in the concept that the processes involved in coping with stress reflect the individuals cognitive appraisal of the situation. These cognitive processes do not simply terminate in static cognitions, but rather

are viewed as phases of activity relating the person to his environment. As Lazarus et al, (1984-a) emphasises:

... understanding variations among individuals under comparable conditions requires taking into account the cognitive processes that intervene between the encounter and the reaction, as well as the factors that effect the nature of this mediation. (p 23)

Stressful emotion and coping, while considered products of the way a person appraises or constructs his relationship with the environment must clearly address the reciprocal nature of the process. Mechanic (1978) highlights the major methodological problem when considering the key role of cognitive appraisal; that is, the use of subjective reactions and reports necessarily involve contamination of the event with the individual's reaction to it. This, however, is balanced by the need for purely objective accounts to be validated.

The Role of Cognitive Appraisal

Cognitive appraisal as the core concept of the process framework can be described as the process of categorising an encounter and making evaluations focused on the significance of that encounter for well-being. (Lazarus 1984, p. 29), describes a threefold approach to appraisal; which is, primary appraisal, that is the initial judgement that the encounter is irrelevant, benign/positive or stressful. Stressful appraisals represent harm or loss, threat or challenge. While harm or loss refers to the situation already experienced, threat refers to anticipated or potential harm or loss. In making the distinction between appraisals perceived as harmful or challenging, Lazarus suggests that the latter implicitly holds the promise of mastery or gain. However, this may also be said of resolved threat or conversely, an 'unfulfilled' challenge which may later pose a threat. Most researchers do not differentiate between these categories, but simply include them as types of appraisals (Appley and Trunball, 1967). It is considered by the writer to be important to differentiate between the categories of appraisals because of the potential, within health care settings, to change the individual's appraisal.

Secondary appraisal is a judgement concerning the individual's evaluation about the coping options available and whether such options will achieve what is expected. The concept of reappraisal is an important and dynamic one in an understanding of the stress response. Reappraisal, the third form of appraisal in Lazarus's framework, is based on new information emanating from person or environment. This may also take the form of defensive reappraisal as a result of cognitive coping efforts. This is a frequently observed stage of the coping process as patients are seen to actively strive in their attempts to come

to terms with new and at times threatening information about their health status. (Lazarus 1980). Reappraisals, are best viewed as cognitive manoeuvres that change the meaning of a situation without changing the situation objectively. Reappraisals may be targetted as emotion regulation, or on the problem itself. The opportunity to change the personal meaning of events is implicit in preparation programmes designed to inform and involve individuals as they prepare for the major life event of admission to hospital.

The functions of coping are concerned with changing a situation which is stressful, that is changing the nature of the stress, or changing the individual's appraisal of the stress. As Lazarus points out, this may be achieved by changing the situation or by changing the persons response to it. A second function of coping proposed by Margatroyd and Wolf (1982), involves the attempt to deal with our thoughts, feelings and body reactions under conditions of stress or crisis without necessarily trying to change ourselves or the situation. The analogues of coping in other disciplines provide an interesting broad spectrum. For example, sociologists refer to the ways in which a social order adjusts to a crisis, while biologists refer to the adjustment of a tissue system or the body to noxious stimuli (for example, Seyles - GAS).

Coping is, on occasions, interchangeable with adaptation. However, as Lazarus, Averill and Opton (1974) succinctly state, adaptation is a broader concept which includes routine modes of functioning. White (1974), considers coping as a sub-category of adaptation that occurs only under extreme conditions of demand. This view, however, places coping as a narrowly-defined concept. While adaptation is a useful generic term, particularly in relation to normal developmental issues, its use in the present study is specifically *not* intended to embrace the unique nature of coping. Within the context of this study, adaptation is intended as a generic term which reflects the normal developmental tasks of childhood.

A distinction is made between problem-focused and emotion-focused coping. Cohen and Lazarus (1983), in a synthesis of the contribution of many writers (for example, Lipowski, 1970; and Magis and Mendelsohn, 1979) cite the coping requirement necessary for hospitalisation for stressful procedures. Among these requirements, to tolerate and adjust to negative events and realities and to maintain emotional equilibrium are two key coping tasks which relate to children in hospital. Problem focused coping refers to efforts directed at mitigating the effects of harm, threat or challenge. Emotion focused coping refers to efforts directed at regulating the emotion itself, whether the focus of such regulation is behaviour and expression; or physiological disturbance; subjective distress, or the interaction of all three (Mechanic 1978; and White, 1974).

As reviewed above, one of the important movements in the adult coping literature has been

the recognition that coping is, to some extent, a temporarily and situationally specific process (Stone and Neale, 1984; Folkman and Lazarus, 1980). The prediction of coping demands attention not only to individual differences, but also to differing stressors. In addition, varying aspects of the coping process ranging from appraisal to encounter to recovery from the stressor as well as different outcomes of coping require consideration. In relation to parents of children who require medical treatments, a further aspect of stress requires to be addressed. A parent is responsible for choosing, on behalf of the child, a particular treatment option. In many instances, for example, emergency admissions, the choice is a formal one consisting in many cases of parental permission for treatments to proceed. The parent in this case signs the appropriate document and is, in many instances unaware that a choice has been presented. The level of anxiety which envelopes such an event directs all parental energies towards securing measures which will help the child regain his normal health. In relation to elective procedures (which constitute 65% of all paediatric surgical procedures in Scotland), the element of proxy consent becomes more of an issue and can assist or hinder the coping efforts of the parents. The issue of informed consent, by definition, involves a two way process of interaction between parent and the medical and nursing team.

The study of coping in children demands another level of complexity. The vast shifts in development during childhood further complicate the assessment of coping strategies if reference is made to existing adult-oriented paradigms.

An understanding of the nature of the stress appraisal and coping processes in children will be achieved only if they are viewed as being staged against a backdrop of rapidly changing perceptions and developmental ability as well as addressing the temporally and situational specificity of the process. Before addressing the issue of coping in the hospitalised child, it is important to review the unique nature of coping in children. This will be presented briefly since it is recognised that coping is a temporally and situationally specific process which is dependent on many variables within the child and within his ecosystem.

2:7 Children's Coping - An Introduction

Traditionally, research in children has focused on areas of stress rather than on coping efforts. However, some studies have been concerned with coping during major life events (Coddington, 1972; and Fontana and Davido, 1984), traumatic situations or change demands such as illness or hospital admission (Coty, Ellerton and Ritchie, 1984; and Lamontagne, 1987), bereavement or other situations involving loss (Brown, O'Keefe, Sanders and Baker, 1986; and Garmezy and Rutter, 1983). In a critique of the above studies,

Ryan (1988) suggests two empirical problems. The first being the limitation of the examination of coping to the observed behaviour thus omitting cognitive coping processes not observed behaviourally. Secondly, the fact that coping strategies may change during extreme stress suggests in Ryan's (1988) view, that data from hospitalised children may not be generalisable to populations of healthy children. The first point of critique is valid but is in fact addressed by most researchers who are aware of the difficulty in assessing cognitive coping efforts in a child-sample of varying ages. The limitations reflect the paucity of appropriately devised instruments which are sensitive enough to tease out the discrete differences between narrow age ranges. This has been done effectively, in very few studies for example, Burnstein, Meichenbaum (1979) and Peterson, (1989). The second point is not considered a valid criticism since the authors set out with research questions related to a hospitalised sample and addressed the limitations of generalisability to other paediatric as well as the child population as a whole. One way of circumventing this last critique would be to have a non-hospitalised control.

How do Children Cope with Stress?

Children's coping is affected by many internal and external factors. Initially, the caregiver functions as a coping agent for the child (White, 1959). The sensitive parent assumes the largest share of coping for the child, altering his/her typical response style to fit the infant's temperament and current state of arousal (Field, Goldberg and Stern, 1980). With increasing development, the parent gradually withdraws support, decreasing screening of potential stressful events that the child may encounter. However, parental expectations may on occasions exceed the child's ability (Azer and Rohrbeck, 1986). In this situation, what appears to be inadequate or inappropriate coping on the part of the child, may sometimes be the result of abrupt or premature withdrawal of parental support. This point is particularly relevant in relation to children coping with stressful medical procedures. The presence of support is a central theme emerging from studies of children coping with stressful encounters, a point which will be addressed by the writer when planning the experimental intervention used in this study. Parents may also be influenced by perceived environmental expectations of their own ability to channel the child's resources along a positive path, as well as hold unrealistic expectations of the child's ability to cope overall with the experience.

Because children are more likely than adults to be dependent on others for coping resources and this dependency is more likely to be viewed as normal and adaptive (Peterson, 1989) the issue of support systems for children undergoing stress is of considerable importance. The literature on such support systems for children is extremely sparse (Bryant, 1985).

However, a parallel concept has developed within the child health care literature. Such studies consider the influence of not only a parent-child system but also expanding systems such as peer group, school and community (Henggeler, 1986). This is an example of the ecological perspective (Bronfenbrenner, 1977). Uniting such emphases with a focus on children's coping can serve to advance our understanding of the external coping resources available to the child. Positive adaptive behaviour (and/or coping) is facilitated where the child is supported.

Coping resources of the child

Limiting a consideration of coping resources to the child's own internal competencies fails to recognise the dynamic nature of (transactional) coping approaches. Discussion of a child's coping resources clearly requires reference to the interaction of child with the environment and address the reciprocal nature of the process. Peterson (1989) in addressing the limitations of studies which focus on the negative effects of various difficult experiences, presents stimulating research reviews which look at how the child can positively manage difficult experiences. Peterson concludes that most children can be characterised as adopting an active information-seeking style or else displaying an avoidant or information-denying approach. Several studies have revealed interesting aspects and consequences of the two coping styles mentioned. For example, Burnstein and Meichenbaum (1979) found that information-seeking children chose to play with medically relevant toys, then later reported lower levels of anxiety after hospitalisation. Knight, Eagles and Evans (1979), extended this finding by showing that children who used 'intellectualisation or mixed defences' (p. 56), had lower levels of anxiety as indexed by physiological measures during hospital stay (for example, urinary cortisol excretion). Seigal (1978), in his research, found that children who sought out medical information were more co-operative and showed a greater level of tolerance of pain than children who avoided information. In her summary of the review, Peterson (1989) concludes that:

... the active end of the scale (on a scale from active to avoidant coping) is associated with more beneficial responding to stressful events and improved psychological adjustment after discharge (p 385).

It is important to avoid artificial and rigid classification of coping resources in children since, if such conceptualisation views coping as a process, the dynamic nature of the process will undoubtedly change across time and situations. Even a very confident child's coping is unlikely to closely resemble coping in an adult (nor is it expected to). The typical array of coping techniques used by adults, such as problem-solving or confrontation, require a multitude of pre-requisite cognitive, verbal and social skills not available to the small

child. In many cases, a precise account of pre-requisite abilities for given coping skills is unknown. Coping deficits within the developing child are more complex and difficult to study than deficits in adult coping.

Peterson (1989) cautions against attempting to conduct research on children's coping at a high level of complexity. Coping in children is a multi-dimensional and conceptually complex process. Mirroring development of the child, research on children's coping requires a solid, less complex base which may gradually expand the requisite knowledge to provide a concise picture of the coping process. Research on children's adjustment to medical procedures serves as an excellent example of investigations that begin with a simple clear model of children's coping and gradually expand from that base to increasing complexity. For example, the work of Hall and Stacey (1979) began with the premise that separation from the care-giver within the unfamiliar hospital environment was the source of the child's distress. The discontinuity of the experience was therefore identified by the authors as the key to an understanding of the child's distress. From this early work, researchers have subsequently built on and expanded the complexity of their investigations of children's responses. These responses should not be subjected to simplistic reduction with a focus solely on either the environment or the child, but require to be viewed in relation to the many inter-related dimensions which influence coping in the child. These dimensions of coping are variously described as, for example, active *v* passive, internal *v* external and emotion focused *v* problem focused. However, as Peterson points out, there is value in beginning study in such a complex area with a single discrete and clearly operationalised discrimination; additional levels of complexity may then be built in.

The present study will address the factors within the child, within the environment and go beyond the immediate situation to look also at the child's response to previous stress. The importance of the child's history in shaping subsequent responses to stress is thereby addressed. It is also important, in the light of previous empirical work (Hall and Stacey, 1979) to place a significant focus on the parents as a powerful influence in the child's response to hospitalisation.

The nature of stress when a child enters hospital, will now be reviewed to provide a framework for the subsequent discussions of preparation for the events which will be presented in chapter 4.

Coping with what?

Although a central question, the answer has frequently been assumed rather than empirically sought. For example, many writers make reference to the stress inherent in

hospital admission of the child but fail to go on to elicit the source of stress, in particular the nature of the stress evoking experiences. In his critical review of the recent studies of children in hospital, Thompson, (1986) cites five key areas which require active effort on the part of the child if stress management is to be achieved.

i). The unfamiliar environment. As complex social units, hospitals share a common feature in that they are organised to function efficiently and are oriented toward group rather than individual needs. This Goffmanian model (1971), although seriously challenged in present day paediatric practice, is still seen as a necessary component of the institution. Unfamiliar surroundings, particularly when coupled with the threat of aversive medical procedures, disturbs the security of the young patient and serves to heighten the perception of stress in the situation.

ii). Separation. While many paediatric hospitals have introduced open visiting and 'rooming in' policies for some parents of sick children, on occasions, these policies do not reflect what is actually taking place. NAWCH (1989) reports that in some situations, parents are discouraged from visiting at particular times. This is usually a passive discouragement and reflects what is omitted from the communication rather than what is explicitly stated. In particular, parents are often requested to leave their child during his exposure to the most stressful procedures (Rodin, 1984, Strachan, 1988). In his study of North American Children's units, Hardgrove (1988), found that 70% of hospitals restricted parental access during tests and treatments, induction of anaesthesia and post operative recovery. While separation from parents is a major concern to children, isolation from siblings, from members of the extended family and from friends is also of significance to the child in hospital (Hall, 1987). The role of the grandparents during this time has been seriously under-researched. McHaffie (1988), found the role of grandparents to be largely supportive and welcomed by parents and by staff during her research of low birth weight babies. To date, no studies have examined the role of grandparents in caring for the sick child outwith the neonatal unit.

iii) Pain and Discomfort. Many treatments involve some discomfort to the child. It is important to point out that pain control in children is extremely difficult to manage, however, no child is left to endure physical pain knowingly. The child's expectation of pain and discomfort within the hospital situation contributes to the experience of stress (Poster, 1983, Bibace and Walsh, 1981, Johnston and Wallace, 1990). Apart from the reality of the pain which accompanies invasive procedures, young children may also perceive pain in painless procedures, for example, having their temperatures taken, or

blood pressure recorded. This is a response to an unfamiliar situation in which the child is attended by strangers and emphasises the difficulty in attempting to separate out the variables which influence the child's perception of the events as stressful. Developmental considerations are important when reviewing children's conceptions of pain and illness. This important issue is discussed in a later section of the review.

iv). **Developmental Immaturity:** Many studies have indicated that distress is most marked in children aged between 6 months and 4 years, as this is the age when selective attachments are forming (Ainsworth, 1982, Poster, 1989). Towards their fifth birthday, children are beginning to maintain relationships during a period of separation. The interference with attachment implicit in admission to hospital may constitute one of the features which make it stressful (Rutter, 1982). While this may contribute to an explanation of the stress observed in the younger child, attention also requires to be given to the school-aged child's distress during hospitalisation. This will be discussed during a later section.

v). **Changes in the Child-Parent Relationship.** Parents are frequently fearful and anxious about the child's illness and may feel some measure of responsibility for its occurrence. Manifestations of anxiety vary, yet many parents exhibit some changes in their behaviour toward their child at a time when the child requires the support and security of a constant and familiar parent-child interaction. Parents may become over-protective, demanding, over-indulgent or restrictive (Robinson, 1987, Pruitt and Elliot, 1990). Parental expectation of the child may alter. A frequently heard entreaty in a children's ward is: 'Be a big boy/girl don't cry' or similarly, 'Don't let the nurses think you are a baby' (personal observations of the writer). This observation may suggest that parents expect an adult oriented pattern of behaviour which according to Hall (1987), may be more indicative of perceived environmental restraints, than parental expectations of their child's behaviour. For example, parents may feel that a display of unco-operative behaviour in the child, may be interpreted by the staff as a reflection of lack of competence in the mother. The writer has observed many instances of parents actively attempting to stifle their child's spontaneous responses to the hospital. There exists a wide gulf in the understanding of the role of the parents and the staff expectations of them. This important point has not been explored in the literature. The measure of perceived control which characterises the hospital environment is a further factor in the stress engendered when a child and parent enter that environment for the first time. Although as Jolly (1981) amusingly points out, the child who has repeated admissions soon learns to manipulate the situation to his own advantage. While this may refer to the older child adopting a 'survival' approach to his

imposed restrictions, the younger child is less able to negotiate the situation to minimise the stress it presents.

The concurrent stresses in hospitalisation: the unfamiliar environment; separation from family; pain and discomfort associated with illness or produced by treatments; heightened parental anxiety which alters the normal relationship with the child and the fear of death and mutilation, all contribute to the risk of emotional harm during the experience. In addition, the nature and duration of the stress as well as factors within the child and his ecosystem serve to influence the risk of short or longer term emotional and behavioural sequelae (Rutter, 1982, Garmezy and Rutter, 1983). In the absence of effective intervention, the likelihood of ineffective coping and maladaptive outcome is increased.

2 : 8 Coping in the Hospitalised Child

Children who are admitted to hospital experience varying degrees of restrictions on their behaviour and activities, whether or not they feel unwell. They are expected to integrate into the needs of an efficient ward routine , in some instances to delegate self-care with the attendant loss of autonomy. Although the hospitalised child experiences the same developmental needs as his non-hospitalised counterpart, the wide variability of cognitive maturity, which is mistakenly linked synonymously with chronological age, often obscures the child's actual needs. The hospitalised child requires a degree of autonomy to encourage continuity of self-esteem, particularly to maximise perceived control over the events. Having briefly presented the nature of stress during childhood admission to hospital, it is now relevant to review the modes of coping with stress employed by children.

To consider children in isolation from family and peer groups is clearly unhelpful. Therefore, attempts to understand coping in children implicitly follows an ecological perspective. This perspective addresses the integration of the psychological and wider sociological nexus. Goodyer (1988) while acknowledging the diversity of responses to stress in children urges this integrative approach where the responses made by children may be studied in context.

It is not possible to define an event as a stressor without also making reference to the properties of persons that make their well-being in some way vulnerable to that event. Karoly, Stefan and O'Grady (1982) reminds us that there is no way to separate the interaction of the two complex systems, the environment and the individual, without destroying the concept of stress as a relational and cognitively mediated phenomenon. In

addressing this reciprocal determinism, the question should be asked, what is it about the individual and the situational context that produces appraisals of harm, threat or challenge?

Threat and challenge are the key forms of stress appraisal relevant to the present study. The significant feature of threat as distinguished from harm or loss is that threat enables the individual to engage in anticipatory coping. Janis (1958), in studying the role of cognitive preparation for effective coping, reported that a moderate level of anxiety prior to surgery was predictive of satisfactory post-hospital adjustment. These findings were challenged by Vernon (1966), Leventhal (1989), and Johnstone and Wallace (1990) who failed to find evidence that cognitive preparation among adult patients was related to anticipatory fear or 'the work of worrying' (Janis, 1958). Burnstein and Meichenbaum (1979) in their examination of the applicability of Janis's conceptualisation to children undergoing surgery ask specifically whether a child's appraisal of threat of a stressful situation leads him to prepare for and work through that experience; and, if the child's defensive position and anxiety-level are related to these procedures of preparation and resolution. The results of the study were significant. High defensive patients, that is children who did not experience pre-surgical anxiety, thus did not experience stress-related thoughts and fantasies, were left unprepared for the distress of hospital and therefore did not engage in the work of worrying. Burnstein concludes that these children went on to experience more post-event emotional distress and disturbance, than did children who were low defensive and did engage in pre-surgical anxiety and stress-related fantasies. As will be advanced in the 'Preparation' section (chapter 4), a fine balance requires to be drawn. Having a knowledge of the child's emotional and cognitive development, together with an assessment of mediators of the stress are central variables to be considered in the individual/environmental interplay. The parent as expert in the knowledge of the child's responses, together with an awareness of the role of the parent as a mediator of stress, are important factors which will be considered in the present study.

Challenge appraisals are characterised by pleasant emotions (Lazarus, 1984-b). A caveat is relevant, however, in that challenge also introduces uncertainty. The unfamiliarities can, in the young child, foster imagining based on creative fantasies rather than concrete reality. Threat and challenge are particularly evident in children's responses to hospital admission for elective surgery. The relationship between threat and challenge appraisals can change as the encounter unfolds. For example, the child who views admission to hospital as more of a threat than a challenge can alter his perceptions to that of more challenging through changes in the person-environment encounter, or because of cognitive

coping efforts. It is a salutary observation, however, that the change may also be from a positive to a negative dimension; that is, the child who has experienced positive pre-hospital preparation may re-appraise in the light of an inappropriate incident or unwelcome environment. Novel situations, for example, will result in appraisal of threat only if some aspect of it has previously been connected with harm. Novelty encourages appraisal based on knowledge of the event. This is well-documented in children's appraisals of the stress of hospital admission and is advanced in relation to unfamiliarity (Prugh, 1958; and Vernon, 1966), strange situations (Gellert, 1958) and coping with the stress of the unknown (Hetherington, 1984).

Attempts to examine the coping behaviour of hospitalised children have been made (Hollenbeck and Susman, 1986; Peterson and Shigetomi, 1981; Grey and Hayman, 1987; and Forquer, 1982). In many studies, however, the results are confounded by including both coping and outcome behaviours. Appraisal of a stressor involves several simultaneous processes in the child. At a cognitive level, the child must relate current stimuli to his recall of similar past encounters. The child must also define the parameters of the event, such as the potential intensity and duration of the stimuli, evaluate the likelihood of the event occurring and locate the event in his appreciation of time.

It is clear, therefore, that the onset of coping is dependent on the child's memory, which in turn is largely dependent on developmental level (Duncan, Whitney and Kunen, 1982) and strongly influenced by anxiety and affect (Izard, 1986; and Bartlett and Santrock, 1982). Johnston and Salazar (1979) assert that memory of past medical encounters may be absent or distorted. Conversely, Hetherington (1984) contends that past medical experiences are frequently the subject of "retrospective magnitude" (p.32), particularly in the pre-school child whose capacity for realistic appraisal of threat based on past experiences is limited. A further position is offered. Bartlett and Santrock (1982), found that many pre-school children report that they are unable to recall having experienced physically painful events considered to be commonplace in childhood, for example, earache, sore throat, painful coughs. The authors interpret this finding as indicative of either not having experienced the events at all or, as is more likely the case, children have experienced such events but do not recall the stressor, or are reluctant to re-experience the event by describing it. If a child is unable to place the forthcoming event in any kind of prior experiential context, appraisal becomes increasingly difficult. As Vernon (1966) asserts: "...a key contributor of upset in hospitalised children is the element of novelty in the situation" (p.1238).

In practical terms, how do children apply active coping with the events which

collectively constitute hospitalisation? Within the 'institution' of the children's hospital, children strive to hold on to dignity, individuality and autonomy. They evolve a variety of coping strategies and employ a number of symbols in the process. Beuf (1979, 1989), in a most perceptive account of strategies adopted by children admitted to a teaching hospital in North America, described categories ranging from 'wild kid'; 'gregarious host'; 'embracing the sick role'; the 'junior medical student'; and 'withdrawal'. While these typologies present a useful practical handle on coping strategies, a rigid adherence to them would be clearly unhelpful. Often a child will employ more than one strategy. Also, children who do concentrate all their efforts on one coping strategy may not evince all the characteristics associated with that category. In addition, Beuf (1979) does not address the possibility that an overlap within the categories may occur. For example, clinical observations of the writer found that at different stages of the coping process, children may be observed to engage in 'withdrawal' while 'embracing the sick role'. The caveat of the role of central intervening or primary variables is clearly applicable. Age; social class; sex; previous experience with stressors; as well as family structure are examples of such variables.

Symbolic Literalism - an Important Coping Strategy

The special role of symbols is addressed by many writers both in developmental (Kagan, 1983; Izard 1984) and in nursing and related literature (Beuf, 1979; 1989; Lamontagne, 1987). Children use and interpret symbols most literally, recognising an almost direct connection between the symbol and what it is intended to represent. This symbolic literalism is particularly relevant to children's coping efforts during hospitalisation. Children locate a symbol that is, in its way, a crystallisation of the emotions and ideas they need to express. For example, the small child undergoing a blood test may have no words for anxiety or the desire for the process to be over. However, during repeat venepunctures the young child is observed to cry for the 'plaster', that is the dressing has become associated with and thus a symbol of, the end of the ordeal. A similar, frequently observed example, is the child who attempts to remove his identity bracelet which is a central part of any parent's/child's hospital admission procedure. In this instance, the child sees a connection between the bracelet and his enforced stay in hospital. Many child psychologists assert that symbols are of much greater importance to children than they are to adults, simply because children lack the cognitive ability and verbal skills to express complex emotions. The implications for health care professionals is clear if frustration and high levels of anxiety experienced by child patients is to be avoided.

Careful attention must be paid to the way a child copes with stimuli in his environment

before he is prepared for surgery. While the children who intellectualise may want to hear every detail of the upcoming experience, the children who engage in denial often cover their ears, trying to block out all the information. These latter children would probably do best with little information and a great deal of supportive, nurturing care both in outpatient departments (at the time of the first contact with the hospital), and in the hospital.

Numerous theoretical questions concerning the nature of children's coping processes remain to be answered. The questions of whether and when children habituate to routine medical procedures, some of which are painful, requires further investigation. The contributive effect of factors such as age, previous experience, coping responses and other individual differences which suggest how well children cope must be studied further before we can develop optimum intervention for a given child. The above points which encapsulate the variability of the coping behaviours of children, will be addressed prior to planning the experimental intervention for this study. It is to the role of key individual differences that we now turn.

CHAPTER 3

INDIVIDUAL DIFFERENCES

The previous section which reviewed the stress and coping literature and informed the theoretical framework of this study, also highlighted further important issues to be addressed by this research which investigates the responses of parents and children in the medical setting. The key role of individual differences has been a recurring thread throughout the stress and coping literature. The issue of personal meaning and differences in the individuals response to situations are integral concepts of Lazarus' stress and coping paradigm. A further level of complexity is introduced when studying the responses of children to stressful events, that is the need to address the important developmental issues which attend childhood.

3:1 Developmental Considerations

This section will review the literature relating to the child's emotional, social and cognitive development only insofar as it influences his adjustment to the hospital environment. A brief review of attachment theory will inform the issue of mother-child separation during hospital admission. Finally, the child's conceptions of health, illness and medical treatments will then be discussed in relation to paediatric hospitalisation.

Introduction.

In reviewing developmental considerations, several important themes are relevant to the present study. These include the present state of knowledge in relation to understanding children's cognitive development and how nurses in clinical situations relate to the child's cognitive stage. In addition, the influence of society's perception of childhood is important in casting some light on how past expectations of childhood have influenced present developmental theories.

During the last six decades, society has begun to view the childhood years in a different light, regarding this developmental stage with greater tolerance and increased knowledge. Historical concepts concerning children that previously were influenced by culture, personal experiences, socio-economic factors and limited knowledge, have been changed by social pressures, developmental theories and research. Although childhood has been re-examined and re-defined, this critical growth period remains a current social

issue. Three key developmental theories gained popularity during the child development movement. The psychoanalytic theory (Freud, 1963, Bergmann, 1973), the Piagetian model (1954, 1962), and the behavioural position (Watson, 1954 Bandura, 1977). With subsequent research, each theory has become identified with specific aspects of child development. In combination, these theories are used as a basis for current child development practices in relation to health care and education in particular. Divergent implications for child care and education were ultimately derived from the three principal theories. The resulting eclectic approach is currently used as a conceptual tool when evaluating issues relating to development in childhood.

No single theory can provide a complete explanation of this developmental process. Instead, each approach is used as a reference point for assessing needs and developing interventions. In addition, these reference points provide valuable information which may be used in institutional settings, for example, the hospital, where common denominators concerning child development are especially helpful when assessment of individual needs and abilities are frequently necessary.

From a view of children as little adults gradually building the data base of information required to be a socialised member of society, we have moved to an appreciation that what children know about life is qualitatively different from the adult perspective (Bibace and Walsh, 1980). This clearly implies that it is not simply the case that children know less about the world than adults, or that their views can be judged as right or wrong according to an adult frame of reference. The cognitive apparatus with which children perceive and conceptualise the world is different.

Traditionally, nurses have based assessment and intervention with children on a general understanding of the stages of cognitive development described by Piaget (1952, 1954, 1959). Recent researchers in the field of cognitive development have pointed to the limitations in Piaget's theory and have presented alternative ways of conceptualising the way children think (Rosch, et al, 1976; Nelson, 1981; Siegler, et al, 1981). Two alternative methods of conceptualising children's cognition that is, information processing and script representation are described by the above authors. (The reader may refer to the references given for an account of the approaches). The main thrust of the critique levelled at Piaget's work is simply that children's cognitive abilities are underestimated in the qualitatively distinct stages described in which the structure for organised thought differs from stage to stage. For example, the work of Rosch and colleagues (1976) placed the emphasis of organisation of knowledge not on deduction and logic, but rather on what is practical and useful. Similarly, Siegler (1981) discussed recent discoveries of unexpected cognitive strengths in infants and young children. Empirical evidence that children can

take perspectives other than their own (Donaldson, 1986), understand simple number concepts (Nelson, 1981), use memory strategies and organise knowledge in practical and useful ways are all significant findings in cognitive research in children, and the findings have implications for the way in which children respond to health care as well as wide ranging implications in relation to how children learn.

Piaget's theoretical stages of sensorimotor and preoperational development did not predict these abilities until a later stage. Indicative of the climate of the time of Piaget's work, this finding is analogous to the considerable advances in our understanding of the needs of children during stressful encounters. The early research provided a frame of reference on which to build a greater understanding of children. Similarly, the attitude which predominated at the time of Piaget's early research did view children as 'developing adults' rather than as unique individuals capable of considerable cognitive and emotional strengths. This knowledge has clear implications for the way in which nurses relate to young children in hospital and will be built upon in the present study.

While age norms in Piagetian terms, for example, describing and classification are approximate, the sequence of development is invariant. Piaget proposes that cognitive stages are linked to chronological age. There is however, evidence of cognitive regression in sick and hospitalised children (Blos, 1978, Parrish, 1978). It is also thought that health history interacts with age to influence illness concepts, producing less sophisticated concepts in the younger child and the converse in the older child (Campbell, 1975). Piaget proposes that the child in the pre-operational stage of cognitive development has many important intellectual strengths. In particular, the very young child is capable of identity and functions. The notion of identity is thought to derive from the child's perception of his own body growth and is later generalised to the world of objects. Functional relationships in the environment are also perceived by the pre-operational child, although in an incomplete way. Piaget refers to these functions as semi-logic. It is important to remain aware of the strengths of the young child as well as the commonly cited 'limitations' when researching children's adjustment to novel environments and situations. The widely reached conclusion that hospital is stressful, often extends to the assumption that all responses of children in hospital reflect this stress and that all responses arise from immaturity (Bowlby, 1973, McGlowry, 1988). This is a mistaken assumption. Some studies describe even the very young child demonstrating considerable strength while coping with the reality of hospital (Ferguson, 1979, La Montagne and Hepworth, 1991). This finding lends further support to the studies referred to above, (for example, Siegler, 1981). Other investigators describe how the child benefits from the hospital experience, finding it both a learning and maturing one. For example,

Vernon, (1966) describes how some children in his sample were perceived to have 'improved in behaviour' as a result of their hospital experience. Careful critique of these and subsequent findings are necessary to avoid inappropriate conclusions being drawn about the beneficial effects a stressful experience. This important issue will be re-addressed in a later section.

A further aspect of Piaget's work of importance to this study, concerns the ways in which the child produces an account of his reality, referred to as the figurative aspect of cognition (Piaget, 1962). The first way is through perception, a system which functions on the senses and operates on immediately present objects and events. It is through this perception that the child achieves a record of the things in his surrounding world. This record may be inexact, a point of particular importance when preparing children for stressful procedures. A further part of the figurative aspect is mental imagery, an important issue when children experience a pre-admission hospital visit. This imagery refers to personal and idiosyncratic internal events which represent absent objects or events. The issue of memory being closely bound up with the figurative aspect of thought. The empiricist view that perception stamps a literal copy of reality on the individual child is criticised mainly on the grounds that no child is a passive organism upon which reality may impose itself. Rather, in keeping with Piaget's contention, current psychological thought (Donaldson, 1986,) asserts that the child assists in the construction of his own reality thus addressing the influence of operative structures of figurative knowledge. This insight is important in relation to planning an intervention designed to prepare children for the forthcoming event. That is, through the child's perception he receives a vivid picture of the hospital ward. It is essential that this preparation should be controlled, planned and entirely appropriate to his stage of development if the effect of such initiatives are to be positive in terms of helping the child to manage the pre-admission phase and cope with the event of hospitalisation.

The influence of memory on approaches to preparation of the child for stressful events, as well as the after effects of paediatric hospitalisation are significant. Piaget distinguishes between memory in the widest sense, that is the individual's ability to retain over time the potential to exhibit learned schemas or operations. Memory in the specific sense refers to the child's ability to retain over time information concerning particular events, people and so on. Piaget's hypothesis states that specific memory is influenced by intellectual operations which serve to organise and shape memory. The child recalls not what he has seen, but what he knows, memory being the result of an interaction between knower and known (Ginsburg and Opper, 1979). The importance of an awareness of developmental stages and the individual variability within them is an

important consideration when a child enters hospital. The potential to apply a theoretical framework which applies also, developmental principles is presented as a result of this review. Changing the child's appraisal of a situation which is normally judged to be stressful, may be achieved if a knowledge of the way in which a child perceives his world is applied to an understanding of stress and coping in the medical setting.

Separating mother and child in the context of hospital admission is consistently documented as causing upset (Vernon, 1966; Melamed et al, 1980, Peterson, 1989). Previous empirical studies have documented the positive benefits of support for the child (Davenport and Werry, 1979). It is to a brief discussion of the role of initial attachments as they influence the child's responses during in-hospital care that we now turn.

3:2 Maternal Child Attachment in the Medical Setting.

The effects of separating mother and child: Theories and Evidence.

The importance of the family as a formative influence on the child's personality is paramount. This is particularly the case during early childhood. Lewis and Rosenbaum (1974) described the family as the matrix within which the child develops, the area where his strongest emotional ties are formed and the background against which his most intense personal life is enacted. Anthony and Kuppenik (1974) describe the family as the most studied, least understood of human groups.

McHaffie (1988), makes the salient point that critical review in the area of mother/child attachment has demonstrated the difficulty in interpreting the findings reported from studies of 'attachment'. The key problems relate to the inconsistencies in strength and direction of the findings as well as a "lack of an unequivocal measure of attachment" (p.46).

While many writers would argue that the identification of behaviours which reflect attachment is fraught with difficulties, recognition of such behaviours is an important issue to address in relation to studies of children in hospital. This is particularly relevant since part of health care treatments are conducted during parental absences. A knowledge of the child's attachment behaviours will therefore contribute to the nurses individual approach to care for these children.

Given the difficulties inherent in effecting interpretation of attachment studies, the

writer adopts the position put forward by Melamed (1976), that is :

...attachment behaviours in the medical setting are interpreted as being those behaviours which indicate a strong need for continued maternal (paternal) presence - the extent to which the mother still occupies a central position in the child's life. (p.35).

While the age of the child is frequently cited as being an indicator of his/her autonomy in the medical setting, for example, 'don't cry, you are a big boy now', the preceding section has cautioned against using a child's chronological age as a predictor of his developmental stage.

Separation from parents is frequently cited as a source of stress for hospitalised children (Nasera, 1978, Thompson, 1986). The medical situation often evokes anxiety because the child is separated from the parents (usually the mother) during aversive procedures. Even when the parent is present, medical procedures are often carried out by unfamiliar adults. This latter situation may be analogous to anxiety elicited by stranger approach. Some important implications from the maternal deprivation studies following Bowlby (1951, 1973) and Spitz (1949) and Bretherton and Ainsworth's study (1974) of stranger approach situations, relate to the degree of bonding of the parent and child. The early work of Bowlby (1951) and the Robertson's (1971) vividly portrayed the dramatic short term effects of separating a child from his mother, as a result of hospital admission or care within a residential nursery. The initial evidence also suggested that early separation could result in longer term disturbance, generally of a psychiatric nature. Understandably, the suggestion of lasting harm following mother/child separation in early childhood caused considerable concern and led directly to an increased awareness of the needs of the institutionalised child.

Although it is important to attend to the social climate of the day and the limited empirical evidence available to further inform the issues raised by these early pronouncements on the care of children, Wolfkind and Rutter (1985) make the point that all the authoritative statements imply that we understand what constitutes 'good' parenting and an optimum child rearing environment. In fact the positive aspects of child rearing practices have to date, been seriously under-researched. Rutter (1982-b) also makes the general point that acceptance of the statements made in the past about the cause of disturbance in children has led to our failure to recognise our ignorance. He further contends that it is not the ignorance per se which is harmful, but rather our 'knowing' so many things about children's well-being which have not been empirically tested. If

research is indeed the act of scientific enquiry, the search for truth and not the statement of knowledge, will be enhanced by further empirical studies, particularly those set up to replicate the studies referred to above.

The circumstances of separation play a major role in determining how the child reacts to the separation, as well as influencing the long-term effects of the experience. For example, whether separation is preceded by discord and disharmony and the child is ultimately admitted to the care of the local authority for an unspecified period of time (Wynne and Hull, 1977). Whether admission to hospital is planned, thus allowing time for adjustment, or whether the result of an emergency. Howells (1963), argues that the quality of the care received, rather than the separation itself dictates the impact of hospitalisation on a child's mental health. This point is argued by many writers (for example, Peterson and Brownlee Duffeck, 1984, Pruitt and Elliot, 1990), who cite observing caring and committed nurses delivering a high quality of care to children who are profoundly distressed by the absence of a parent, or by the hospitalisation experience. It is important to note however, that separation does not necessarily equate with stressful experiences (Melamed et al, 1986). Other separation experiences may be free from unpleasant connotations, for example, planned visits to relatives, Cub or Brownie camps. Stacey et al, (1970, 1979) and Roche and Stacey (1991), present evidence which suggests that brief happy separations may help a child cope with more protracted ones. This research did not, however, follow children across stressful separations. No work has been done which assesses the effect of 'planned happy separations' on future hospital admission, although many studies do elicit data relating to the child's previous experience of separation.

Two classes of environmental events serve to elicit attachment behaviour in the child (Brown, 1975). The first is an enforced or accidental disruption of the close proximity of the child and mother, the second is the perception of threat. Admitting a child to hospital without a parent can be seen as invoking both kinds of event. It is important to address factors other than separation which may influence the attachment behaviour of the child in the medical setting. For example, change in the mother/child interaction which was reviewed in an earlier section, may also pose a threat to the security of attachment perceived by the child.

The Effects of Brief Separation: Admission to Hospital.

Roche et al, (1990) argues that Bowlby's hypothesis about maternal deprivation has received wider acceptance among health care professionals than any other social research

finding. However, it may also be argued that Bowlby's model translates more readily into a medical model based upon biophysiological events which encompass deficit theories, than sociological explanation could achieve. These explanations are based not on individuals or even dyads, but upon systems of inter-relationships between sociological entities that have no reductionist biological base, as in organisations, professions and value systems (Hall, 1987). The response of hospitals to the evidence of the maternal deprivation model has sometimes been to select, for practical action, the most significant features and to ignore the rest. For example, the finding of disturbance in younger children translates to a policy of open visiting and rooming-in facilities for the identified 'vulnerable' age group (usually the under fives), but diverts attention from possible disturbance of a different nature in older children.

The observation that a young child may be acutely distressed in hospital cannot be disputed. Many authors have recorded such phenomena (Edleson, 1943, Prugh, 1958, Robertson, 1970, Douglas, 1975, Rutter, 1988, Rodin et al, 1984 and Pruitt and Elliot, 1990). In addition the clinical observations of the writer confirm the presence of such distress across age group and differing stress encounters. The phases of protest, despair and detachment outlined by the Robertson's (1971) describes the three stages of the child responses to separation and traumatic experiences. These phases described by the empirical studies of the Robertson's, are crucially influenced by the qualitative aspects of the institutional care. This finding suggests that the child is able, under conditions of separation from the natural mother, to establish bonds with an alternative care-giver. Given that the effects on selective attachments are most important for children in brief separations, Rutter (1981-b) offers three caveats. First, most separation experiences involve more than separation from parents. Separation from siblings, peers and the familiar activities of every day living are also involved. Stresses include medical procedures to which the child is subjected. The circumstances of separation are also important. In relation to hospital admission the difference between elective and emergency admission with the latter's lack of preparation and attendant crisis present highly significant contrasting situations. The third caveat relates to the individual differences in how children response to stresses, including that of separation.

One of the principal recommendations of the Platt Report (Ministry of Health, 1959) was the provision of facilities in children's wards for the mothers of young children, (generally the under fives) to remain with their child throughout his hospital stay. Over three decades later, the provision of these essential facilities remains at best patchy and at worst absent.

The following article "A Parents' Voice" first appeared in the 'Lancet' in 1965. It is quoted in full here with the aim of highlighting the impact of admission to hospital on a young child and her family:

"My little girl Dawn, was admitted to hospital for a tonsils and adenoid operation when she was 3 years and 3 months old and she had never been anywhere without me, was very shy and did not get on with strangers. I took Dawn to the hospital at 2.15p.m and was allowed to stay with her until 3 o'clock and told that I could return for visiting hour from 5 - 6pm. When I returned, I was told by the little boy in the bed next to Dawn that she had cried since I left her at 3 o'clock, her little face was quite puffed with crying...I was told I could not visit the next day because she was having the operation , but they said I could telephone at 12 noon. Wednesday, 17th I telephoned at 12 noon and was told that Dawn had the operation and was satisfactory. I asked if I could visit, but was told not to after an operation but I could telephone at 6pm. I again telephoned the hospital at 6pm. and was told that Dawn was bleeding heavily but not to worry and to ring again at 8pm.

This I did and was told that the surgeons had taken her back to the theatre to stop the bleeding and they said I could telephone at 9.30pm. This I did and was told that she had not come round yet but the bleeding had stopped and I could ring again at midnight. This I did and was told that Dawn had come round and was sleeping peacefully. They told me not to worry but to go home and sleep and telephone the hospital at 10.30am next morning. ...I must point out that each time I rang up I begged to see my child but they said there was nothing to worry about and I could not see her. Thursday, 18th, 10.30 am. I telephoned the hospital, spoke to the sister and was told that Dawn was a little improved and that I could visit at 4 o'clock. I arrived at the hospital at 3.50p.m and was asked to wait because the doctor was with Dawn. A few minutes later I was told that Dawn had collapsed but not to worry because the doctor was doing all possible. I asked if I could go to her, but was asked to wait. As I waited I prayed to God to help my little girl; a few minutes later the ward sister came and said that my dear Dawn had passed away at 4.15p.m. so you see although I was there I couldn't see her even though she was dying. They took me to see Dawn then but it was too late for my love to do it's work... Other mothers in the ward who were allowed to see their children because they had not had operations that day ,told me that on the day of the operation Dawn cried constantly for me, and this I believe caused the bleeding...

I do believe that my little girl died of pneumonia but I also think that if I had been with her it might have had a different ending because she wouldn't have needed to sob her heart out if I had been by her side and if she hadn't cried she wouldn't have lost so much blood, and she would have had more strength to fight the pneumonia with.

...If this letter can help in any way to get another youngster his mother's care after this operation, I shall be pleased for you to use it..."

MacCarthy and MacKeith.

Reprinted from the Lancet 1965, in the Archives of Disease Childhood, 1985.

While the factors which precipitated this tragic episode cannot be known from this account, the mother clearly believes that the stressful experiences endured by her child were confounded by separation.

In her study of parents whose children were undergoing cardiac investigations, Alderson (1990) reports that to the parent the "single most important thing is that I can stay with my child". There have, of course, been many progressive changes in the care of children and their parents during the past two decades. Many centres now actively encourage parental participation and view the family as integral members of the team rather than visitors to the child. However, as the recent reports from NAWCH (1989) suggest, parents are still unhappy about many aspects of provision during the child's period of hospital care. For example, the provision of rooming-in facilities still appear to be limited to paediatric hospitals. Children cared for in units with paediatric wards/beds have no access to such facilities. In addition, the situation within paediatric hospitals is far from ideal. The changing nature of the medical and surgical treatments available to children carry with them, on occasions, higher risk. Technological advances change the nature of the stress experience and impose additional strain on the parents. Facilities then tend to be reserved only for parents of children who are seriously ill.

While separation from mother has been seen as a major cause of stress, both during and following hospital admission, a broader perspective is required to understand the links between the individual, familial, professional, institutional and structural levels of hospital care as they affect children. Hall, (1987) proposes a model of discontinuity to analyse the experiences of children parents and staff. The Swansea study, (Hall, Stacey, Robinson and Pill, 1979) concluded that the balance of priorities between therapy and welfare require to be re-appraised. The effects of hospitalisation are both cognitive and emotional; children have to interpret and construct a meaning for the events in which they are implicated and by which their behaviour is controlled. It is apparent in this review of the separation studies that children find this adjustment less traumatic in the presence of the mother and or father.

Summary.

Review of the separation studies offers an expansion from the earlier unidimensional approach used to study the effect of hospital on children's psycho-social development. Hall (1987) recommends that an examination of children's responses should include an awareness of the social factors operating on children in terms of their past experiences and learning. In addition to separation from the mother for at least brief periods during hospitalisation, the child's separation from routine activities, other relationships and the familiarity of daily living are also stressful (McGlowry, 1988).

Rutter (1989), concludes that a child's separation from his family constitutes a potential

cause of short term stress. Moreover, even the short-term effects cannot be regarded solely as a response to maternal separation. Although separation experiences have an association with the later development of anti-social behaviour (Rutter, 1981-a, 1989, Garmezy, 1983), this is due not solely to the fact of separation itself, but also to the events which accompany the separation. Parents are necessary mediators between the immature patient and the potentially overwhelming contact with the range of new experiences. They filter and partly control experiences, thus assisting mobilisation of the child's coping resources.

The challenge to change the factors which operate within the environment can be accepted by nurses as they address the evidence that the effects of hospitalisation on the child extend beyond separation. For example the role of the parents within the hospital as partners in their child's care has been, until recently, largely unfulfilled (Cardiff - Care by Parents Scheme, 1990). This study will address the value of parental involvement in the child's care during admission. In addition, reassurance of parent's involvement may be given to the child before admission if, in turn, the parents are adequately informed about their role and the importance of maintaining regular contact with the child during his hospital stay. This is facilitated by an individual approach to preparation which this study aims to test.

At the same time, it is important to identify the individual differences within the family and within the child himself in terms of temperament and vulnerability and resilience. The literature on the study of temperament is prolific. Empirical work with hospitalised children is extremely sparse. The relationship between selected personality factors and children's responses to hospitalisation is important. Understanding the child as an individual engaged in a variety of activities and relationships requires addressing the nature of these unique characteristics. The reader is guided to the following sources for a review of the work available: Thomas, Chess and Birch (1963), La Montagne (1984), Berger (1985) and Lyon and Plomin (1989).

It is to a discussion of the individual child's vulnerability and resilience that we now turn.

3 : 3 Vulnerability and Resilience

In a wide ranging review of the literature of children's responses to stress, Michael Rutter (1985) wrote:

There is a regrettable tendency to focus (gloomily) on the ills of mankind and on all that can and does go wrong ... The potential for prevention surely lies in increasing all knowledge and understanding of the reasons why some children are *not* damaged by chronic or intermittent stress. (p.602).

During the last decade the concept of protective factors has become firmly established in the field of psychological 'risk' research (Garmezy, 1987; Masten and Garmezy, 1985; Rutter, 1979, 1985). This concept stems directly from the related notion of resilience, the term used to describe the positive pole of individual differences in people's response to stress and adversity. Rutter (1989), in describing a shift of focus from vulnerability to resilience, also proposes a shift from risk variables to the process of negotiating risk situations. Garmezy (1985a; 1985b) concludes that three broad sets of variables operate as protective factors. These are:

- 1) Personality features, for example, self-esteem;
- 2) Family cohesion and an absence of discourse; and finally,
- 3) The availability of external support systems that encourage and reinforce a child's coping efforts.

The third antonym of risk variables stated above presents a challenge to the professionals when a child is admitted to hospital (since the focus on protective mechanisms and processes encompass the range of experiences to which the child and his parents are exposed on admission to hospital). This final variable is of central concern to the present study and is seen to influence the coping responses of child and parents. Preparation for paediatric hospitalisation is an application of external support systems *par excellence*. The preparation initiative should therefore take account of the many variables which influence the responses of the child and his parents.

A number of over-lapping sets of observations have begun to yield clues to the roots of resilience in children. Significant findings have come from the few longitudinal studies which have followed the same groups of children from infancy or the pre-school years through adolescence (Block, 1980; Block and Block, 1981; Murphy and Moriarty, 1976; Werner and Smith, 1982). Some researchers have studied the lives of minority children who did well in school in spite of chronic poverty and discrimination (Kellan and Branch, 1975; Garmezy, 1981; Gandura, 1982; Clark, 1983;) and on the coping patterns of hospitalised children (Vernon, Foley and Schulman, 1966; Peterson and Shigotomi 1981) while Wallerstein and Kelly (1980) studied the effects of parental divorce on young children.

All of these children have demonstrated considerable psychological strengths despite a history of severe and-or prolonged psychological stress. A combination of personal competence and some unexpected source in their care-giving environment either compensated for, challenged or protected them against the adverse effects of stressful life experiences. Some researchers refer to these children as invulnerable (Anthony, 1974), others consider them to be stress resistant (Garmezy and Tullugren, 1984) while Werner and Smith refer to the positive outcome in their study of 'vulnerable but invincible' children.

Characteristics of resilient children have been variously described. Werner (1984) cites four central characteristics which these children have in common:

- i. They have an active evocative approach toward solving life's problems, enabling them to negotiate successfully an abundance of emotionally hazardous experiences.
- ii. A tendency to perceive their experiences constructively, even if they were negative events.
- iii. The ability, from infancy on, to gain other people's positive attention.
- iv. A strong ability to use faith in order to maintain a positive vision of a meaningful life. (p. 76).

A caveat must be offered to this optimistic picture of children who show resilience. Resilience is concerned with individual variations in response to risk. While it is the case that some children succumb to stress and adversity, others overcome life hazards. However, resilience can not be seen as a fixed attribute of the individual. Children who cope successfully with difficulties, at one point and in one situation, may react adversely to other stressors when their situation changes. If circumstances change - resilience alters (Rutter, 1989).

The concepts of vulnerability and of protective mechanisms are more specific and more narrowly defined than that of resilience. The essential defining feature is that there is a modification in the person's response to the risk situation. It will be appreciated that in this respect vulnerability and protection are the negative and positive poles of the same concept, not different ones. The analogy of physical immunity is often used to explain vulnerability and protective mechanisms in psychological stress by an understanding of the concept that positive physical health comprises exposure to, and successful coping with, a small, usually modified dose of the infectious agent. Similarly, protection against excessive effects of psychological stress stems from the adaptive changes that follow successful coping. An interactive process may then be described as applying to both

vulnerability and protection. Rutter (1989) asks if there is any point in retaining both concepts of vulnerability and protection, if in reality they are no more than opposite poles of the same concept. We talk about immunization as a protection just as we do the preparation of children for hospital admission. Logically we could say that lack of immunization and preparation are vulnerability factors, but prefer instead the positive concept of protection because the action taken concerns the positive pole.

Werner (1984) states very simply that:

... as long as the balance between stressful life events and protective factors is manageable for children, they can cope. But when the stressful life-events outweigh the protective factors, even the most resilient child can develop problems. (p. 68)

The implications for child carers are clear -- the balance can be restored by either decreasing the child's exposure to intense or chronic life stressors, or by increasing the number of protective factors, e.g. competencies, sources of support. Attempts to modify the intensity of the stressor and to build on the child's coping strengths form the core of the experimental intervention envisaged in the present study.

The implications of the studies on vulnerability and resilience are important in caring for the hospitalised child. For some children, some stress appears to have a steeling rather than a scarring effect (Anthony, 1974; Garmezy, 1983; Rutter, 1989). It is important however to identify the presence of a shifting balance between stressful life events which heighten children's vulnerability and the protective factors in their lives which enhance their resilience. Werner (1984) maintains that, as long as the balance between stressful life events and protective factors is manageable for children, they can cope. Conversely, Werner also suggests that when the stressful life events outweigh the protective factors, even the most resilient child can encounter difficulty. This balance concept, although apparently simplistic, in fact demands a knowledge of the individual child's strengths and ways in which encountered 'weaknesses' may be circumvented. The result could be attempts to restore the equilibrium, either by decreasing the child's exposure to intense or chronic life stresses, or by increasing the number of protective factors, for example, competence and sources of support. Rutter (1989) turns the focus on protective processes or mechanisms, rather than vulnerabilities. These processes, by definition involve interactions of some nature. Rutter concludes by commenting that protection from the effects of stress in childhood:

... does not reside in the psychological chemistry of the moment but in the ways in which individuals deal with life changes ... particular attention needs to be paid to the mechanisms operating at maximum key life events when risk trajectory may be re-directed onto a more adaptive path. (p. 329)

This position requires an understanding of personal meaning of the events considered challenging or threatening. Therefore it is important that a study which examines children's responses to medical stress should also access data on responses to previous stressors, since the effect of past encounters is known to colour the child's responses to new situation, particularly if the child can identify some similarity between the events (Garmezzy, 1983). It is to a review of the literature dealing with children's conceptions of illness and medical treatment that we now turn.

3 : 4 Children's Conceptions of Illness and Medical Treatments

The implications of cognitive development theory for the medical care of children are considerable, since it is in real situations that children have most opportunity to test existing concepts and develop new ones.

There has been an encouraging increase in recent years in studies aimed at discovering from children themselves what are their understandings of illness, pain and hospital treatments (Perrin and Gerrity, 1981, Reissland, 1983). The literature reviewed by Vernon, Foley Sipowicz and Schulman (1965), suggests that young children view hospitalisation and illness in terms of punishment, mutilation and abandonment. The predominant position of investigators conducting this early research was that misconceptions of this sort contribute to children's psychological upset during and after the period of hospitalisation. Despite the prevalence of this belief, Vernon and his colleagues note that "there has been relatively little discussion of the ways in which interpretations of hospitalisation and illness contribute to psychological upset" (p. 1240). Also, apart from clinical accounts, there is virtually no empirical evidence that misconceptions of hospitalisation, health and illness result in psychological upset (Thompson, 1986).

Post 1965 research has continued to examine and document children's health care concepts and knowledge, including the misconceptions characteristically expressed. The first of these concerns children's beliefs about the cause of illness and reasons for medical treatment. This research was pioneered by Bibace and Walsh (1980, 1981), who asked children from 4 - 12 years of age a series of questions about the cause of illness in general as well as more specific illnesses such as measles and heart problems. The writers were able to identify three stages in the child's thought. Between the ages of 4 - 7 years, children often attribute the cause of illness to 'magic' or witchcraft. Other children in this age group view illness as a form of punishment. Some writers (Steward and Steward, 1981) ask what role the adult plays in the child's misconceptions of illness. Adults often predict problems if the child does not conform to adult guidance. For example, warnings about

wearing warm clothes in cold weather, or climbing trees which to the adult appear hazardous. It is little wonder that the child who subsequently develops a chesty cold or alternatively falls from the tree breaking a limb, feels that the incident is indeed the result of his own misdemeanour. Similarly, the study by Peters (1978) invited children to present written accounts following viewing a series of pictures containing cues designed to elicit comments pertaining to illness; of these children who identified a causal agent, sixty per cent indicated that the 'ill character' in the story was responsible for his or her own illness. Interestingly, sex differences in the designation of causal agents were apparent. Girls were more likely to attribute the illness to the characters own actions than were boys. The boys more frequently implicated other persons or environmental factors. Peters concludes that analysis of the content and wording of the stories indicates an acceptance of self-causation and "a pervasive implication that illness results from disobedient or impudent behaviour". (p.148). This important methodological flaw, which on the one hand encourages the researcher to address developmental differences within the sample, while on the other aims the same questions to a group of 8-10 year olds, renders this particular study less valuable. However, replication could attend to the prevention of bias in the questions asked and gather some interesting data on the question of gender difference in illness conceptions.

Treatment of illness was also frequently interpreted by children as a form of retribution. In half the references made to treatment children indicated either explicitly or implicitly, that the intent of the treatment agent was punitive or hostile. Despite the narrow age range of children studied by Peters (8 - 10 years) age differences are apparent in his findings. Younger children are reportedly more likely to view illness as a self causal state and treatment as punishment, than were their older counterparts.

Eiser (1985), in her study of illness conceptions among 7 - 10 year olds, identified 'contagion' as a major causal explanation. At the least mature level of this stage, the child is likely to believe that illness is contracted by physically touching another person, object or animal and is also likely to over generalise this new knowledge. Thus children are inclined to believe that non-contagious illnesses are also catching (Kirster and Patterson, 1980). Younger children then prove to be less firmly in command of the concept of contagion than older children, over extending it to inappropriate ailments and to a lesser degree, failing to appreciate the mechanism of disease transmission. This is an important observation, particularly in relation to the recent awareness of H.I.V. infection. In this situation, the adult population appear to have difficulty conceptualising disease prevention and spread. Indeed the adult cognition bears close resemblance to the child's

conception of illness contagion. The need for further research in this topical and important area, where assessment of knowledge and the factors which determine its application in child settings, for example the playground, is urgently required.

Studies which Examine the Conceptions of Healthy and Ill Children

A limited number of studies have investigated the health care conceptions of both populations (Williams; 1978, Rutter; 1980, Rumfelt; 1980). Inclusion of both groups of children in research should permit the comparison of the prevalence of self-blame or punishment explanations used by each group, thus enabling the researcher to determine whether such conceptions are limited to, or more prevalent among, ill children. The findings indicate that, when punishment explanations are provided by subjects for a given set of questions, they are offered by healthy as well as hospitalised children. This research challenges Brodies' (1974) suggestion that healthy children interpret illness in a fundamentally different manner, than do those who are hospitalised. However, Rutter (1980) also provides evidence of children's belief in their own responsibility for illness. Groups of diabetic, scoliotic and healthy children, aged eleven to thirteen years, were questioned concerning their feelings of responsibility for positive and negative experiences associated with mild or severe forms of illness or injury. Children's belief in self responsibility for negative events was found to be significantly greater than for positive events.

In contrast to the preceding studies which indicate substantial belief in the self-causation of illness and its attendant treatments. Rumfelt (1980), found little indication that either hospitalised or non-hospitalised children perceived the actions of the nurse in a punitive light. This is an interesting finding on two counts. Firstly, a wide range of treatments given by the nurse was experienced by the hospitalised sample, the non-hospitalised group were given pictures of nurse performing the tasks. Some treatments were considered to be invasive and painful (giving injections, attending to wound dressings). Second, the age range studied by Rumfelt was limited to five year olds, who are expected to be on the threshold of increasing autonomy, while still in the pre-operational stage of cognitive development. Replication of these findings would be required across a wider age range and the specific nature of the objective stress made more explicit. Despite the methodological problems, Rumfelt's findings suggest that children are able to compartmentalise *aspects* of the overall experience and have perceptions based on personal meaning of these aspects, rather than the whole.

Within a developmental framework, the comments and assumptions that children make

regarding health related issues that, on the surface appear amusing, silly or haphazard are in Bibace and Walsh's view part of an orderly developmental sequence of knowledge. Studies which examine children's illness concepts as a function of chronological age provide less evidence of the relationship between cognitive development level and illness concepts because age is simply not an accurate predictor of cognitive maturity (Bibace and Walsh, 1979). The literature appears to support the hypothesis that children's illness concepts develop in a systematic and predictable sequence consistent with Piaget's (1929) theory of cognitive development (Campbell, 1978, Eiser, 1985). Fresh research which empirically tests the recent studies of cognitive abilities in younger children (Nelson, 1981, Siegler et al, 1981), are required in this area.

Medical procedures, health and illness are issues about which children tend to vocalise spontaneously because they are directly concerned with the children's own bodies and therefore are of great personal concern to him or her. This may be in sharp contrast to other social domains in which children's conceptions often must be inferred from their behaviour.

Much of the behavioural disturbance reported by staff and parents may be an attempt on the child's part to solve the cognitive dilemmas and discrepancies introduced by illness, medical procedures and hospitalisation. Shire and Spivack (1978) have noted that what adults often see as disruptive or problematic behaviour is really the child's attempted solution to a perceived problem.

One of the most pervasive theoretical issues in cognitive development research is the nature of the relationship between cognition and affect. This area requires particular attention in the field of health studies because of its potential for evoking an emotional response in children. Another central issue is whether the level of cognitive maturity shown in a child's response, in one domain, correlates with some other measure of his or her cognitive ability in another aspect of his functioning. Many authors, seeking to find an unbiased developmental indicator of children's conceptions of health-related issues, correlate children's conceptions of, for example death with their performance on standard Piagetian tasks of cognitive development (such as conservation). Other researchers begin by assessing the child's developmental status with respect to certain forms of reasoning (for example, identity) that are assumed to be fundamental to a health-related concept. Given a normal population of children, Bibace and Walsh (1981), use age as a rough indicator of cognitive level in relation to health issues; while acknowledging that predictions based on age are not always accurate. Discussions about what constitutes a 'normal range' of children are inevitable as a result of Bibace's studies, an issue not

addressed by the writers. Cognitive development cannot be fully understood without an appreciation of the role of individual difference or between-subject variation.

A related and significant issue concerns the variability in levels of reasoning shown by the child within a single content area (within-subject variability). The methodological problems are apparent when the researcher attempts to assign children to a single stage even though they show reasoning reflecting more accurately, their own developmental level. Perhaps the example of Crider (1981) who talks about level of conceptualisation, rather than stage is a relevant one to apply to the discussions of the wide individual differences in children's emotional and cognitive development.

There is little empirical research to aid the understanding of the cognitive components of the child's response. The research literature is sparse, although very rich and prolific clinical vignettes that include children's spontaneous comments about medical and surgical procedures in hospital have been reported for some time (for example, Jessner and Blom 1952; Prugh and Staubs, 1958; Kris and Solnit, 1964; Freud, 1965; and Bergmann 1975). Most of the previous work has been focused on the defensive or protective function of observation by paediatric staff members. There have been few attempts at analysis of the level of conceptual development that these responses represent.

Children's coping strategies and the potential for cognitive and emotional growth, stimulated by the complex experiences that accompany illness in our society, have not been studied. More attention is now being given to the positive aspects of the experience of hospitalisation and illness (Azarnoff, 1984, Peterson, 1989). The opportunity for research to study the potential for benefit within this situation hitherto perceived as wholly negative, arises as nurses and other professionals recognise the abilities of the child within a supportive and caring environment. The staff within the hospital environment are able to provide that support and level of human caring as the child mobilises his coping resources to meet the demands of that environment.

The distinction between the child as a passive recipient of environmental information and the child as an agent, actively constructing his or her own reality, is particularly important in preparation initiatives. The opportunity exists for such programmes to relate to the needs of the individual child and his parents. This study will address these issues in the light of the insights gained from a review of the developmental considerations, of maternal/child attachment in the medical setting and of an awareness of the child's conceptions of illness and medical treatments. It is to a review of the literature which addresses preparation for paediatric hospitalisation that this review now turns.

CHAPTER 4

THE CHILD IN HOSPITAL

4:1 The Nature of Stress When the Child is Hospitalised

Introduction

This section is concerned with sharpening the focus to an understanding of the specific nature of the experiences to which the child is exposed during his admission to hospital. Attention will then turn to a discussion of the preparation approaches previously applied and to a review of the key variables which influence preparation. It is pertinent to recall the present trend in preparation programmes, that is a process of cut-backs and cost containment has led to a virtual cessation of the programmes which previously operated within paediatric health care.

The child entering a hospital thinks, acts and reacts as he does as a result of an array of differing past experiences, present occurrences and demands of situation, as well as expectations (or fears) of the future. While it is clearly the child and parent as individuals that the nurse welcomes to the ward, for the purpose of study, it is necessary to fragment the experiences of the child and his/her parents.

The nature of stress when a child is in hospital envelopes a range of new experiences which pose a threat to the emotional equilibrium of the young child. As has been discussed in the section on vulnerability, it is not possible to define an event as a stressor without reference also to the properties of the person that make his/her well-being in some way vulnerable to that event (Garmezy, 1983). This position offers a sharp critique to the view of isolated contributing factors which has been put forward to explain upset behaviour, for example, Vernon's (1966) concept of upset in the hospitalised child was based on the identification of factors such as unfamiliarity, discomfort and so on, without reference to the personal or environmental qualities of the experience. The central question requires to be asked -- what is it about the individual and the situational context that produces appraisals of harm, threat or challenge? There is no way to separate the two complex systems, the individual and the environment, without destroying the concept of stress as a relational and cognitively mediated phenomenon. However, for the purpose of

study, factors pertaining to both systems require to be addressed independently, given that the interactionist perspective will be a continuing thread throughout the discussion. This is important, since the environment clearly affects the child as the child actively engages his environment. This recurring arrangement is on-going and present in all adaptational encounters in a fashion implied also by Bandura's (1978) term "reciprocal determinism".

From the last four decades of research on child hospitalisation, one observation has emerged quite clearly: the experience of hospitalisation superimposed on the experiences of illness and pain increases the probability that latent adverse effects will evolve (Trad, 1987).

All hospitalised children, irrespective of their illness, their relationship to their peers, the quality of hospital care, or their preparation for hospitalisation, react at least minimally to the experience (Prugh et al 1958). Despite the increasing awareness of the adverse effects of hospitalisation, Prugh (1983), who has studied the emotional impact of hospitalisation for over thirty years, charges that hospitals still rigidly adhere to many of the 'adultmorphic' practices and policies thought to pose the most serious risks to children. Although the extreme form of hospitalism as described by Spitz (1949) is rare, as are the devastating circumstances of separation described by Dawn's mother in chapter 3, the risks of childhood hospitalisation cannot be minimised.

In sum, Trad, (1987) suggests that the degree to which any aspect of childhood admission to hospital exposes a child to the risk of maladaptive behaviour patterns (depression), is a function of the nature of the illness and the time of onset (p. 143). This alone is insufficient to explain the variability of responses of children to similar situations and procedures. A review of the literature supports the view that illness creates risk through its impact on temperament and attachment as well as through its impact on the child's sense of control over his/ her environment. Pre-school children are identified as being at greater risk, during this time. Children have few resources for controlling their environment at this age, and therefore have the most tentative sense of physical and psychological competence. Moreover, illness evokes conscious and unconscious fears about the newly established self.

Frequency of hospitalisation and length of stay represent two significant factors in determining the likelihood of maladaptive outcomes as a result of hospital care. While most studies suggest that a single isolated stay in hospital rarely leads to long-term damage, even if the emotional distress is acute and persists after discharge from hospital (Douglas, 1975; Quinton and Rutter, 1976; Rutter, 1979), the follow-up of the children

continued for a relatively short time and did not reflect response to subsequent medical and social stressors. In contrast, evidence indicates long-term significant effects of the child who has been hospitalised repeatedly at an early age. The findings indicate the occurrence of learning and emotional problems of a persistent nature in a sample of the children (Bowlby, 1969; Rutter, 1989).

The Determinants of Upset.

In a recent review of children's and parents' reactions to hospitalisation, Prugh (1983), in his treatise on causes of upset, cites a variety of restrictive practices that are loosely referred to as "forced immobilisation": confinement to bed/ cot, restraint for specific medical procedures, for example, intravenous infusion and use of sedative drugs.

Many of these factors however are a function as much of the illness and prescribed treatment as of hospitalisation per se. The key phenomenon unique to hospitalisation, separation of contact with parents and siblings, is recognised as the pivotal dimension capable of limiting or exaggerating the effect of hospitalisation and surgery.

For example, Prugh (1983) concludes that separation from the mother may, in some cases, be more significant than the medical and surgical procedures undergone by the child. However, the effect of the hospital experience per se must not be minimised. Skipper et al (1968), in a prospective study, found that the hospital experience itself caused anxiety in a proportion of the sample who had parents rooming in, the effects of surgical procedures being held responsible for some of the upset.

A number of behaviour problems have been observed in children hospitalised for surgery (Gellert, 1958; Prugh et al., 1953; Robinson, 1987; Peterson and Mori, 1987). Indeed, it would be difficult to postulate the absence of at least minimal anxiety in children undergoing surgical procedures. As a paediatric nurse, the writer has frequently observed a wide variety of responses to the same procedure within similar age groups. The variables which influence response to hospitalisation and treatments are addressed throughout this section. The widely held view that hospitalisation and its concomitant procedures such as surgery and anaesthesia cause psychological upset in a significant number of children has some empirical support, which in Goslins' review, (1978), is far from unanimous. The findings of earlier studies reviewed by Vernon (1965) cite over 60% of children as being significantly disturbed by the experience of admission to hospital for varying procedures. In a review by Kay (1966) the key treatment variables which appear to affect frequency and degree of disturbance are anaesthetic procedures. Presence of the

mother during induction of anaesthesia and specific types of induction, concealed painless intravenous, rather than routine intravenous or inhalation induction, were reported by Kay as having a mitigating effect. A more recent study (Lord, 1988) suggests a anaesthesia charter which presents a balance between safety considerations and the desirability of parental presence during anaesthesia induction procedures. It is significant to note that the charter also addresses the impact of the event on future reactions to anaesthesia or health care procedures. (NAWCH. Charter -- annual report, 1988).

The impact of pain as a stress agent in children's experience of hospital has been addressed indirectly in relation to attempts to control and/or alleviate pain in children. Although the issue of pain in children is beyond the scope of the present review, it is relevant to the present discussion to identify the perception and expectation of pain, in relation to the nature of stress when a child is in hospital. Vernon (1966) found that the degree of pain experienced during hospitalisation produced no systematic effect on the child's behaviour after hospitalisation, although the author failed to present a measure of how it affected children at the time they experienced it. Essays pertaining to children's experience of hospitalisation (NACWH.) report little pain-related data: "It is people and what they said and favourite dolls (or absence of them) and above all being away from family and home which are remembered with great intensity" (reported in Hailes -Took,1975). However, these studies make no reference to the child's experience of pain of major operations, of chronic debilitating illness, or of repeated painful, invasive medical procedures experienced during the course of diagnostic and therapeutic regimes.

Of the studies which have researched more momentous childhood illnesses, a major methodological problem continues to be separation of the pain experience per se from the effects of the illness, the expectation of painful procedures and the subsequent perceptions of pain as the child's pain threshold is significantly altered during the course of the experience. (Fisher and Reason,1988; Steptoe1990; Johnson and Wallace,1990). Also, the nature of the objective stress is thought to be less important in determining adaptive outcomes than the child's perception of that stress. Bergman, (1979), makes the salient point that for children and their families, there is no such concept as the 'minor' paediatric surgical operation. Bergman goes on to comment that the qualitative difference is a matter of degree rather than kind and the presence of any invasive technique, particularly if accompanied by anaesthesia, signals a high risk factor to many parents who have a realistic appraisal of the situation. The fear of anaesthesia cannot be ignored. While many parents and adult patients accept the expertise of the specialist giving the anaesthesia, many reports indicate the persistence of a 'illogical and at times

uncontrollable fear experienced by a parent when children undergo anaesthesia' (Lord,1988,p.1) While exploring the relationship between cognition and affect may be a useful area of enquiry. It is also important for the nurse and the anaesthetist to assess parental knowledge, to know about past experiences which may colour present fears and to spend time listening to parental concerns. This emphasis on past 'history' is an important component of the preparation initiative applied to this study.

The nature of stress when children are hospitalised has changed in degree rather than in kind in the past three decades. In an early study Gellert (1958) concludes that several aspects of the hospital experience may be considered uniformly upsetting regardless of the developmental stage of the individual child. Separation from parents and the home environment combined with inadequate support from parents rated highly as determinants of extreme upset. While this may be expected to relate to every child in general terms, the degree of upset crucially depends on many complex and interacting variables, among which age and developmental stage, previous experience of separation, pre-admission relationship with parents and preparation for the forthcoming events, are seen to contribute significantly to the child's perception of the experience. (Skipper, 1966; Prugh, 1986).

Having addressed the inter-relationship of some important variables in relation to the nature of the stress when a child is hospitalised, attention requires now to turn to an account of the opportunity to mitigate the stress experienced by the child and his parents as they prepare to enter hospital. A review of the preparation literature is now presented.

4 : 2 Preparing Children for Hospital

The risk of disturbance to children can be reduced by the promotion of a better understanding of the hospital's place in the community.

(Children in hospital -- the Which report. 1980)

Why prepare a child for hospitalization? Peterson and Toler (1988), in asking this provocative question, remind us that less than three decades ago this was not a naive question. The earlier research (Pre-1965) was conducted within a climate of restrictive visiting practices, absence of rooming-in facilities for parents of sick children, authoritarian ward routines and a very limited awareness of the needs of the sick child and his family.

The most damning evidence concerning the negative effects of hospitalisation was offered

by Douglas, (1975) who reported on the long term follow-up of more than 1,000 children born in 1946 and admitted to hospital before the age of five years. By sound methodological comparison with similar control children who had not experienced childhood hospitalisation, Douglas concludes that in adolescence multiple problems were observed which could be related to hospital admission. These problems were of a learning and emotional nature. Although these findings were seriously challenged, Quinton and Rutter (1976), in an attempted replication of Douglas' findings, finds that at least some of the effects of hospitalisation were damaging to children, leading to both short-term and long-term problems.

The Hospital as an institution has changed significantly during the past two decades. Paediatric wards are more child oriented, anaesthetic techniques are considered safer and medical and surgical advances have accelerated into the technological era. Although this latter development brings with it many benefits to children requiring invasive treatment, it also brings specific stresses which relate to these technological advances. Children are, on the whole hospitalised for a shorter period when possible, and encouragement to resume normal activities after treatment is given. Perhaps the most significant change affecting the entire hospital milieu as well as having profound impact on child and his family, is the attitude of staff to the needs of the hospitalised family.

A large percentage of staff involved in caring for children in hospital avow to the philosophy which underlines the Platt recommendations. However individual hospitals and within them individual wards tend to make their own decisions about the care of children. Indeed, the report of the Consumers Association (1985) highlights the concern felt by parents of children in hospital in relation to the quality and provision of care, particularly, in relation to "supportive care prior to admission". It is important to ask why changes designed to meet more fully, the observed needs of child and parent should meet with such delay in implementation in many areas (NAWCH.,1982).

The relationship between knowledge and action is a relevant dichotomy. To identify areas which require change in nursing and health care practice generally, is simply the starting point for change. Real change in established practice requires not only empirical evidence to justify its implementation, but also a commitment and willingness to change on the part of the professionals involved. Notwithstanding the very real issues of resource limitations and variable availability of continuing up-date programmes for in-service education, the reality remains that many of the changes still required may be implemented within existing resources.

A basic message from a review of the literature is the complexity of the problem of children's vulnerability to hospital. A corollary of this is that attempts to implement change should not proceed on the simplistic model of causality. Preparation for hospital is an example par excellence of this point. If attention is paid to the many variables discussed which influence how the individual child copes with the event, then preparation clearly requires to be more discriminating. Hall and Stacey (1979), in proposing their 'discontinuity' theory, suggest that we require to understand the details of the relationship between a child's place in the home and subsequently in hospital in order to understand the significance of the distress which may be felt in hospital. The authors go on to explicate their theory by highlighting attention to the sharp contrast between the child's experience at home and subsequent experiences during hospital care. Preparation programmes require to address the 'discontinuity' which the child experiences on admission to hospital. While the extent of this gulf between home and hospital is now much less than in 1979, when Hall and Stacey reported their findings, the present concerns relate to the qualitative aspects of discontinuity experienced by the child. For example, few surgical units encourage visits by siblings of the sick child and on the whole peer visiting is not permitted, therefore hospital is still 'distanced' from the accepted norm in relation to the child interacting with siblings and with friends. The rationale for these practices is obscure, since the previous explanation of increasing infection risk is now in the light of empirical studies, no longer a viable one.

In addressing the question, is there still a pressing need for preparation? - a useful conceptual approach would suggest four ways of answering this question.

One method would be to examine some of the factors that have been documented as causing anxiety and assess the hospital environment, to see whether these factors still apply: factors such as an unfamiliar setting (Vernon, 1965,) strange and threatening equipment, (Cassel, 1969, Johnston and Wallace, 1990) painful procedures and lack of control (Eiser 1985, Fegley, 1988).

A second approach using negative outcome criteria, may be to explore the reactions of children who were psychologically unprepared. Studies continue to report a variety of post-hospital behaviour disorders (Wolfer and Visintainer 1979; Sylva, 1990). Prugh and Jordan (1975) in what they refer to as an "angry chapter" describe a variety of psychological disturbances due to hospitalisation, these include severe anxiety and aggression. The authors' anger stems from their premise that these negative reactions are preventable by appropriate preparation and support.

A third approach to the initial question of the need for preparation may be to generalize from other theories and research findings. For example, do people find that information that enhances a sense of cognitive control over events also lowers their stress? Thompson (1986), in his review of the preparation literature, asserts that at least in the older child and adult this is the case. Also, is there a long-term cost to be met in reacting 'poorly' to stress in terms of avoiding stressful situations (and labeling oneself as ineffective) and the concomitant influence on self-esteem and autonomy. The adult focused literature shows a rapidly accruing evidence of such cost (Bandura, 1977). Therefore the beneficial effects of short-term 'manageable' distress in relation to subsequent coping in the medical and social context is addressed (Rutter, 1981-a, 1989).

The fourth and more objective approach, may be to demonstrate the continuing need for children's preparation programmes by reviewing the current literature on the utility of preparation programs, in an attempt to provide empirical demonstrations of benefit.

Most paediatric nurses and psychologists believe that preparation is useful and of value. Issues relating to the nature of preparation applicable to the individual child and family; the temporal issues involved; preparation of staff to implement such programmes; continuing empirical support to evaluate the efficacy of preparation as an on-going process; cost-effectiveness; and finally, the need to address the hitherto unasked question, is preparation harmful, all require to be addressed prior to setting up preparation programmes.

Previous studies have laid the foundation for many differing preventative techniques. However, research which examines processes which are perceived by nurses to be of theoretical relevance alone may be over costly in a climate of cost containment and inappropriate staffing levels. As indicated in the introduction to this study, many preparation programmes established in the 1970's and 1980's are discontinuing at an alarming rate (Azarnoff, 1982). The reasons for the falling off of established programmes in Britain is undoubtedly the emergence of a new cost containment philosophy at all levels of health care (Lothian Health Board, 1991), disseminated by central government and imposed by local health boards. Although adequate empirical validation for the effectiveness of such measures is apparent from a review of the North American literature, few such studies have been undertaken in Britain. The challenge for nurse researchers is apparent when we look at the recent available figures, available only from North American studies. Azarnoff and Woody (1981) in their survey of acute paediatric hospitals (USA) conclude that only 33% of hospitals caring for children continue to offer preparatory programmes for elective medical and surgical admission. In Britain the

picture is less clear since no available recent research has been conducted. Many anecdotal reports from children's wards within adult hospitals and from paediatric units suggests that preparation takes place on an 'an hoc' basis and while fully accepting the need to address the issue of preparation, no structured programmes currently exist in many areas. The few hospitals that do practice preparation as part of family care have implemented their policies with minimal additional funding.

Many writers explore the question of why previous research on psycho-social preparation is not having a direct impact on practitioners (Azarnoff, 1984; Peterson, et al, 1985; Eiser, 1985). Three key interrelated areas are worthy of consideration. These are cost-effectiveness, the influence of comparative research, and finally we need to state a specific goal for prevention and access dates related to that goal.

Cost effectiveness is not restricted to the financial effects of a programme. Other concerns, such as the interpretation of the commitment to care, as well as awareness of the professional input required is of moment. Clearly a careful assessment of resources is necessary, but the motivation and commitment of the team are paramount in ensuring the success of preparation initiatives. It is argued also, by the writer, that such programmes may be implemented with no additional resources, simply the re-allocation of resources already present. This point is discussed in relation to the analysis in chapter 12.

As an area of research enquiry becomes more developed, it is important to proceed beyond the demonstration that 'some preparation is better than no preparation'. This leads the nurse into a comparison of commonly used treatment approaches. In the absence of comparative research, nurse practitioners have no criteria for selecting a particular procedure among the vast array of techniques demonstrated as superior to a no-treatment control. The inevitable outcome is that the technique requiring the least cost and effort is often selected, and applied indiscriminately to all age groups, with varying efficacy.

Clearly in order to select the best treatment, the nurse practitioner needs to address, not only available resources and comparative research, but also, must be able to clearly conceptualise and communicate, the specific goal for prevention. The overall purpose of techniques used to prepare children for health care treatments is the alleviation and/or prevention of distress and anxiety. Consequently, researchers employ a variety of measures of anxiety and distress including behavioural or observational, self-report and psychological variables.

The research area of psychological preparation for children's medical procedures has

always included a number of pragmatic, methodological and clinical challenges (Peterson and Mori 1989, Melamed and Seigal,1975). Clinical challenges include reducing children's and parents' distress during procedures that are perceived as both psychologically and physically threatening. It is important to impress upon practitioners the importance of using well-evaluated methods of preparation. Non-validated techniques run the risk of being ineffective or even harmful, by sensitizing patients already at-risk.

Peterson (1985) describes the variety of arenas in which such contributions can be made. These include the preparation of well-children for future possible hospitalisation; the preparation of children for non-surgical treatments, for example involving invasive procedures (e.g. blood tests, cardiac catheterisation) and the preparation of children for surgery.

The Preparation of Well Children for Possible Hospitalisation.

In her study (conducted in America) "Preparing well-children for potential hospitalization" Azarnoff (1985) put forward a convincing case for such initiatives. As a logical extension of preparing children several days or weeks prior to a stressful procedure, it is also seen as the only form of preparation possible for acute emergency admissions (Peterson and Brownlee-Duffeck, 1984). Most of this literature describes preparation programmes that serve large numbers of children, but fails to offer empirical validation of these programmes, other than consumer satisfaction measures and the author's opinion. Some programmes are conducted within primary schools and use authentic medical equipment, for example, stethoscopes, needles, x-ray films or plaster casts (Trouten, 1981). Other approaches have combined school and hospital attendance. For example, hospital tours for pre-school children which begin with short, repeated information giving sessions in the classroom combined with hospital illustrated stories. A hospital tour then followed one week later (McGarvey, 1983). While all of these programmes have been planned with a well-defined goal, the actual benefit remains illusive. Clearly, only when children involved in the 'well-child preparation' are actually admitted to hospital, will it be possible to evaluate the efficacy. Even the methodological problems of assessing the influence of the many intervening variables may render such programmes difficult to evaluate. Klinzing and Klinzing (1977) attempted empirical validation of well-child preparation. The study involved the showing of a hospital-related video tape recording (VTR) to two to five year olds, depicting a child's and puppet's experiences from admission to discharge. This was compared with the showing of a similar VTR which was non-hospital oriented to a control group of children. The authors reported more positive attitudes toward hospital in the children who viewed the hospital-related

video. This study also reported no age difference, with even two year old children 'benefiting' from watching the video/tape. A major weakness of Klinzing's study is the absence of measures of children's anxiety and fear, also insufficient detail on other measures employed were described.

Laudable though primary prevention in relation to children's hospital-related stress may be, there are two main areas of concern. The first relates to the rationale for such generic approaches to preparation across a wide age range (most of the investigations studied children from two to nine years or from nine years plus). There are numerous opportunities for misapprehensions when introducing hospital related information to children at varying levels of cognitive development. In some instances the child's fantasies may be kindled by misunderstood knowledge, leading to positively harmful perceptions based on fear and mistrust. Clearly, the failure of most studies to follow the children through into the 'real' situation of medical stressors is a significant methodological weakness.

The second point relates to the issues already addressed, that is, the cost-effectiveness of primary prevention. It is of interest to note that no empirical studies have examined the issue of well-child preparation in Britain, although reference has been made to the possible benefits (Hall and Stacey, 1979; Eiser, 1984, Harris, 1979). It is a salutary point that within a system which as yet is failing to adequately meet the need for preparation in children who are known to require hospital treatment, the potential for primary preparation is likely to remain untapped. In essence, these preparation measures require further validation by observing the prepared child's behaviour in health care settings.

In summary, the consensus in Britain appears to favour a low key approach to the preparation of well-children for possible future health care. It is important however that this is not interpreted as a lack of commitment to such initiatives, but rather an approach based on sound developmental rationale with the parent as the focus of attempt. Clearly, the type and timing of procedures requires to be evaluated, as does the parents' views about health care. The comment by Hall (1987) encapsulates the present position "The risk of disturbance to children can be reduced by the promotion of a better understanding of the hospital's place in the community" (p. 46.). The general aim of education about hospitalisation and health care generally is to enable 'hospital' to be perceived as a very normal part of every child's experience. Stacey et al (1970) expresses reservations: "... such education is only partially received because of a general human tendency not to pay attention to what one hopes, therefore in part believes will 'never happen to me' " (p. 109). Given the sound rationale for providing information to the child, one cannot assume that every child acquires what has been presented. The opportunity to change the nature

of the child's appraisal of the stress by way of appropriate preparation has been indicated in chapter 2. During the process of categorising the encounter, the child accesses his/her past 'similar' experiences and uses the present information to subsequently modify and adjust the meaning of the event. In the case of a novel situation the opportunity to prepare effectively depends not only on the approach to preparation adopted by the staff, but also on the meaning of the event, which in turn is highly influenced by the presence of support from the parents. Further studies, employing more sophisticated measures of acquisition, are needed before any conclusive statements can be made about the extent of knowledge acquired by children receiving various preparations.

Preparing the Child for Planned Admission

Preparation for Specific Treatments.

Preparation for invasive procedures has been studied extensively in the nursing and psychological literature. Discrete medical procedures are studied. Some involve clear primary prevention, in which the child is prepared in advance of the encounter. Others involve preparation for on-going procedures which are aimed at lowering current distress as well as preventing distress in future procedures. Many investigators report that children perceive injections and venepunctures as the most fear-provoking events occurring in the hospital (Eland and Anderson, 1977; Poster, 1989). There is, however, little consensus on how to prepare children most effectively for these procedures. Cognitive strategies, often in concert with physical interventions, have frequently been adopted. Ayer (1973) applied vivid mental imagery to help two injection-phobic children deal with their treatment. Other plausible attempts have been made to prepare children for a mixed array of invasive procedures. Fegley, (1988) used contingent versus non-contingent instruction in pre-cardiac catheterisation preparations. Cassel (1969), in his study of a similar area, employed a puppet model, who, as the children observed, experienced the catheterisation procedure presented in a developmentally appropriate fashion. Opportunity to correct misconceptions was presented. The findings suggest that children who received this programme were rated (by the cardiologist) as less distressed on a global rating scale during catheterisation and, after transfer back home, were more willing to return to hospital, compared with the group of children who did not receive this preparation.

Eland (1981) applied a physiological and cognitive re-appraisal approach when he used a skin chilling spray to deflect from the pain of injection. Peterson and Shigetomi (1982) assessed children's response to venepuncture using several coping strategies, for example,

relaxation, self-instruction and imagery distraction. Children in this treatment group were rated as coping "more positively" and were less fearful than children who had received filmed modeling preparation. Given the considerable numbers of children who attend hospital on a regular basis for various treatment regimes, it is clear that measures to influence the child's first encounter with the stress are of key importance to subsequent adjustment. Further research is required in this area in order to individualise approaches used. These approaches require attention to developmental stage, coping disposition, nature of the objective stress, family support, and so on. At present, it would appear that techniques that provide both information and a method of coping actively with the source of fear and anxiety provide the most effective preparation (Rodin, 1983).

Preparation for Surgery

The majority of preparation programmes currently available in Britain, North America, Middle East and Scandinavian countries, are oriented towards preparation for surgical treatments. Many techniques and approaches used have not, as yet, received empirical validation. The literature in this area tends to consist of descriptions of programmes rather than assessment of their value.

Preparation Themes

In their discussion of psychological preparation for paediatric surgical procedures, Vernon, et al (1966) cite three major areas to be addressed when planning preparation. These are:

- a) Giving information to the child;
- b) Encouraging emotional expression, and;
- c) Establishing a relationship of trust and confidence with hospital staff.

Later research advocates the addition of a further two themes: preparing parents and providing coping strategies (Elkins and Roberts, 1984). Implicit in all the above themes is the expectation that each will be presented within a developmentally appropriate framework. A comprehensive discussion of the above themes, their rationale and perceived efficacy may be found in Thompson, (1986).

A number of child and family characteristics may determine individual responses to hospitalisation. (For example, age, sex, social class-Vernon, 1965). Therefore, Melamed and Seigel (1980) make the salient point that patients selected to participate in research be matched across treatment groups on as many variables as possible. However, it is also recognised that psychological preparation for surgery may not be equally effective for all children. Similarly, variables that affect preparation require to be investigated to assess

how such variables interact with preparation procedures as children with different characteristics may require different procedures. For example, as reviewed above, increasing the perceived similarity between a child and the filmed peer model may be associated with greater anxiety reduction, as the child is able to identify with the model and attempt to emulate the coping responses shown by the model. This suggests the need to use multiple models to present a variety of patient characteristics. Addressing the multiplicity of such characteristics, it is considered to be an unrealistic expectation to expect all children to be able to identify closely with the assortment of models produced. A more manageable approach may be to present an effective resource person who can act as an 'interpersonal link' between the representation and individual reality .

The empirical evidence available on the relationship between hospital preparation procedures and the personal characteristics the child brings to the situation have been studied (McGlowry, 1988, Pruitt and Elliot, 1990). These are, for example: age, developmental ability, sex, previous hospital and other stress experiences, pre-hospital personality, coping disposition, timing and length of preparation, nursing care and parental response. The nature of the objective stress, that is the reason for surgery and nature and type of procedures, is also an important consideration.

The question has changed from why prepare a child for hospitalisation? to 'How best can a child be prepared?' In addition, current research is also asking: 'When is preparation best carried out, using what particular techniques?' The large majority of the literature considered in this review has focused on preparing the child alone for stressful medical procedures. Although a few preparations have been directed explicitly towards parents (for example, Skipper et al,1968) and others have included parents as viewers of a modeling film (for example, Pinto and Hollandsworth, 1984) or as coping treatment agents (for example, Meng and Zastowny, 1982), most preparations have been directed exclusively toward the child, and many have deliberately excluded parents and siblings (Faust and Melamed, 1984). The reason for this apparently reductionist approach to preparation research is generally that of the need to address methodological issues of sample size, resources available, as well as the wider philosophical question of practice driving research ; or research subsequently influencing practice. This contentious issue can more appropriately be discussed following presentation of the findings from this study.

Involvement of the family in the child's care has been recognised by paediatric nurses as a key element in positive health outcomes for some time. Such involvement, extending to preparation not only addresses the central role of the parents as the 'experts' in relation to their own child's needs but also may potentially enhance the parental role *during* the

hospital stay as the process of preparation leads effectively into the process of care. Hospital admission is not considered to be an unitary 'life event', but one which has an interactive effect on the child's future, whether the outcome is increased resilience or further vulnerability will depend on many variables. The child's characteristics, the pattern and amount of hospitalisation, the severity of the illness, the nature of the preparation received, as well as the support and involvement of his family, all interact to influence the effects of hospitalisation on the immediate and subsequent adjustment of the child. It is to a discussion of preparation of parents for their role in the child's care before and during hospital admission as well as the need to prepare parents as an implicit health care right, that this review now turns.

4 : 3 Preparation of the Parents

Preparation of the parents for the hospitalisation of their child is justified on the grounds of the potential value to the child as well as the immediate needs and right of the parents themselves.

Well informed parents who understand the nature of the event and who have no excessive guilt feelings about their child's treatments are in an optimal position to prepare the child for hospital admission. (Zabin and Melamed, 1980, p 30).

In addressing the issue of preparation of parents the implicit assumption of parental involvement is made. This involvement may extend to caring for the child while in hospital, but it certainly indicates the emotional involvement of the parent. There are many anecdotal reports (Gellert, 1958, Van derVeer, 1949, Meng et al, 1982) and few empirical studies (Campbell, 1967 Roberts and Strayer, 1987) in the literature which make the association between the level of maternal anxiety and that experienced by the child.

The earliest focus on the negative effects of a child's hospitalisation on the family suggested that anxiety in the mother could reduce her capacity for meeting the child's emotional needs and further, that her anxiety, if communicated to the child, could serve to increase the stress experience of the child during hospitalisation (Skipper et al., 1968). Vardaro (1978) demonstrated that physiological measures of anxiety of mothers and their child patients were strongly related. This emotion contagion theory, described by Van der Veer (1949), has understandably attracted much attention in the child clinical literature. The central tenet of Van der Veer's theory holds that the emotional state of the parents can be transmitted to the child. Wolfer and Visintainer (1979) included psychological preparation of parents in a pre-admission programme. The results from this study show

parents to be more satisfied with preparation and to perceive their children to have 'coped' better overall with the experience, than parents who received the standard hospital preparation, based only on information giving (by letter). However, the absence of an attention control group makes interpretation of the above findings less clear. It is unclear whether the effects were due to the specific nature of the preparation *per se* or to the effect of the additional attention or to factors within the population. In addition, the many intervening variables which influence child and parent anxiety, for example, previous stress, pre-hospital adjustment and so on, were not addressed in the Wolfer study. Attempts are made within this present study to address some of the major methodological problems raised by past studies, principally, absence of an attention control group and failure to adequately address the need to match the sample as far as possible.

Review of the developmental literature (Chapter 3) reinforces the view that the child is an active participant in his environment; he is cognitively assimilating experiences and employing existing coping strategies in coming to terms with these experiences. A main critique of the emotion contagion theory is that it views the child as the passive recipient of parental emotional states, without addressing also the influence of the child on his own level of anxiety and emotional well-being (Bibace et al, 1981). Many variables operate to further inform the emotion contagion theory, a key consideration being the age and developmental stage of the child. In addition, pre-hospital child-parent relationships exert an influence, as do parental coping during other stressful events. Peterson (1989) suggests that parental anxiety stems from the same sources as the anxiety of the child. A lack of information concerning what to expect for one's child (Skipper, 1966; Freiberg, 1972), as well as separation anxiety (Irwin and Lloyd-Still, 1974; Issner, 1973) can influence a parent's reactions. In addition, feelings of guilt (Smitherman, 1979) and feelings of uselessness (Parfit, 1975) may operate unless the parent has a clear view of the importance of her or his continuing role during the child's hospital care.

McHaffie (1988) makes the pertinent point that stressors become crises in relation to the family definition of the event. A logical extension of this premise is that the definition reflects not only previous exposure to and coping with stressful encounters, but also the underlying personal meaning of the event in terms of guilt, feelings of failure and helplessness felt by the parents as they attempt to interpret their own meaning of the events. The significance of parental perceptions to the coping process is an important consideration. This insight will be applied to the present study in relation to the perceptions held by the parents of the forthcoming surgical treatment of their child.

Elkin's et al (1984), cautions against the assumption that child and parent anxieties are

necessarily similar. Reference to the developmental literature confirms the variation of concerns felt by children during stages of cognitive development. In their study on preparation of children for hospitalisation, Wolfer and Visintainer (1975,1979) hypothesised that parents who made no attempt to prepare their child for hospitalisation may have allowed their own level of anxiety and information to determine their children's need for preparation and, thus, were less cognisant of their children's concerns. It appears that relying solely on parental supervision of preparation is questionable unless parents are explicitly made aware that their child's concerns may be different from their own.

Smitherman (1979) argues that parent's rights have been inadequately addressed and efforts to maximise information, preparation and a role as a capable participant require to be made. Similarly, Goslin (1978) suggests that a child's hospitalisation is a life crisis for the family, including siblings and that the mixed emotions the siblings may experience such as rivalry and guilt (O'Meara, McAuliffe, Motherway and Dunleavy, 1983) constitute an additional problem to be dealt with when addressing preparation. To view the child as an intrinsic part of a family unit is to open the way to considering how that unit will function during the hospitalisation of one of its members. The provision of support may then be oriented towards the unit rather than only towards the individual. The role of the parent in hospital is often a source of conflict between parents and health professionals (Hall, 1987, Gillies, 1990). The reasons for this dichotomy stems from a basic misunderstanding of the role and potential value of parental involvement. Much progress has been made but as Thornes (1986) points out, many paediatric units are still a long-way off from implementation of the recommendations of the Platt report (1959) which specifically identified staff and parent relationship as a target for improvement. To create a positive and active role for parents of children in hospital requires reviewing the cultural models of medicine and nursing. Hall (1987) cites a medical report on resident parents in paediatric wards in which the problem for future research is taken to be how to "... define the characteristics of mothers and children most likely to benefit from residential facilities for parents,"(p 726) rather than how to change the ward environment to make visiting and residential stay more satisfying and beneficial for all parents and children (Keane and Garralda 1986).

Attempts to build on the strengths of parental involvement as experts in their child's behaviour (Hayes and Knox, 1984) and as interpreters, co-ordinators and advocates for their children, are recognized as important goals in paediatric nursing in the 1990's. In addition, there is an increased use of the word 'family' to designate a constellation of

significant others whose bond with the child-parent should not be disturbed by hospitalisation. This shift seems appropriate given an increasing awareness of the role of the father which embraces an increased sharing of the nurturant parental role (Lord and Schowater, 1982).

In spite of the many developments aimed at promoting the involvement of the family, there remain many hospitals which fail to provide rooming-in facilities. On occasions, where facilities are present, parents may fail to take advantage of them. Peterson and Shigotomi (1982), in an one-year follow-up study of surgical paediatric patients, reported that more parents identified overnight separation as a stressful aspect of the experience, more stressful than other parameters which included post-operative pain, bleeding or vomiting. Clearly, the parents' attitudes towards 'rooming-in' as well as their level of anxiety in relation to the child's hospitalisation are variables which influence the efficacy of such facilities. In terms of support, the availability of parental companionship in hospital needs to be considered in terms of financial and social as well as psychological consequences. Travel costs and time off work may be barriers to full participation of some parents. The impact of parental as well as sibling absence also exert an effect on the children at home who will consequently be cared for by friends or relatives. Keane and others (1986) suggest that those mothers taking up the opportunity to stay with their child are disproportionately ones with only children; and from higher social class groups. Hall (1987) postulated that reasons for this discrepancy may be higher levels of anxiety among higher social class mothers. However, as observed by the writer while in clinical practice, in situations where parents are not encouraged to stay, and the potential value of their role is not explicitly stated, the more assertive, more articulate higher social class groups generally request 'rooming-in' and thus self-selection results in an uneven distribution of this facility.

Participation of the Father.

A majority of the research reviewed refers to parent responses, actions, anxieties and general attitudes in relation to the child in hospital. In fact, with few exceptions, the parent is generally the mother. This high profile afforded to mother is mainly attributable to research traditions, societal beliefs and the practicalities of conducting research (Thompson, 1986). Perhaps also, the dominance of Freudian theory in the psychological literature has, until recently, placed a particular emphasis on mother-child relationships (Bowlby, 1952; Ainsworth, 1982). Also, in spite of demands for sexual equality and liberation of the woman from the perceived chains of child rearing, many mothers choose the primary role in caring for their children and defend vigorously their

right to maintain it.

As hospitals have encouraged greater parental participation, society's traditional views of parenting now supported by the medical community's belief in the primacy of mother-child relationship, has resulted in a greater number of mothers than fathers rooming-in, and taking an active role in the care of the sick child. An indication that this situation is changing is offered by Lord and Schowalter (1978, 1982) who report an increase in paternal involvement. In practical terms, hospital researchers have consistently found fathers to be less available for participation in their studies and for the most part, have eliminated them from consideration. In effect, a great deal requires to change in relation to society's expectations of the parental role. In a pilot study, Strachan (1988) found only 2% of fathers could be available to assist and support the mother during the child's hospitalisation. Paternity leave, commonplace in some Scandinavian countries, is on the whole, not considered by employers in Britain. Consequently, the status quo remains, unless the child is seriously ill or admission to hospital can be planned to co-incide with father's leave, the mother will continue to take the key role of being with the child in hospital.

Any attempt to involve parents more fully in the care of their children in hospital must face the demographic realities of single-parent families and working parents: particularly mothers who have traditionally assumed the key child care role (Knaff, Deatruck and Kodadek, 1982). Burns (1984) makes the salient point that social attitudes to children's health care will take some time to alter towards equality. It is, for example, interesting to note that in studies of chronic illness in children, mothers are found to have a greater knowledge of treatment, side effects and care than father (Falkman, 1977; Johnson, 1974). Hall (1987) describes situations where there is both economic necessity and social obligation on mothers to work (for example, in Hungary and the Commonwealth of Independent States, where there are in general, fewer opportunities for parental visiting and minimal facilities for over-night stay with a sick child).

The Influence of Social Class on the Child's Hospitalisation.

While it is beyond the scope of this study to review the growing body of literature which relates social class to health outcomes or satisfaction with care, it is important to bring social class into the arena of variables to be addressed in relation to the experience of parents and their children during paediatric health care.

Social class has long been recognised as a key variable which exerts an influence on the

child's response to hospital (Vernon, 1966). Parents' attitudes, motivation and ability to become involved in the events which comprise their child's hospitalisation are also influenced by social class.

The concept of social class is especially relevant to paediatric studies. Graham, (1984) commenting on the importance of social class factors states: "The relationship between social class and health is at its closest during childhood" (p.49). Social class serves as an indicator of the social, economic and cultural differences between respondents and the inevitable impact these differences have on experiences (Bechhofer, 1969). As an indicator also of the environmental factors which impinge on the child's development, social class provides a useful guide (Birch, Richardson, Baird and Harobin 1978). This point is highlighted by Anthony and Benedek (1970) who state:

Children start out in life with systematically different preparation. Indeed, the notion that children were starting out in life with equal opportunities to participate in a wide-open race in which they were all running, had to be modified in two major aspects. Investigation began to suggest not only that they did not all start out with equal opportunity but that they were not even being prepared for the same race. (Parenthood, p. 90)

While all children are vulnerable and likely to experience some stress and / or unhappiness, Pringle (1980) identifies some groups as more vulnerable because of "pre-stressed" conditions. Rutter and Garmezy (1981) support this position and cite large and low income families, single parent families and children living apart from parents, as being particularly vulnerable to the effects of subsequent stressors. While the effects on the children of social class variables are well documented (Vernon, 1966; Stacey, 1979; Greenberg and Rice, 1980), relatively little is observed in relation to the effects of this variable on parental attitudes towards the child's hospitalisation. McHaffie (1988), in her study of parents coping with low birth weight babies, suggests that differences in parent-child relationships in the middle and lower social classes arise from systematically different life-experiences which in turn lead to basic differences in outlook and style. It is frequently reported that, while working class mothers externalise life events and expect to exert little influence upon them, middle class mothers perceive a greater degree of control over life events. While the higher social class parents, on the whole, perceive their child's behaviour as complex and requiring understanding and support, it is suggested that working class mothers fail to understand the complexities of their child's development (Newson and Newson, 1976). In view of the proliferation of key literature and media attention given to issues of child care and development, it is put forward by the writer, that the above account of parenthood is now overly simplistic and indicative of gross generalisation. Anthony and Benedek (1970) explored the value

differences between middle and working class mothers. The authors concluded that middle class mothers tend to express a greater obligation to be supportive to their children, while working class mothers are more pre-occupied by parental and other commitments to impose constraints or to identify occasions for support. In light of the dominant issues of concern which beset working class mothers, e.g. basic survival in material terms, acceptance of externally imposed standards provides a modicum of security.

Social class differences during hospitalisation of the child are important in relation to involvement in the child's care, communication with professionals and with the child, and finally in relation to parental expectations of the experience.

The Impact of Social Class on Parental Involvement

The practical difficulties in relation to travel, care of siblings at home and arranging time off work are clearly key issues of concern for some social groups. Graham (1984) described a "paradox of successful caring" in which the physical constraints of space and distance, the financial constraints of poverty and the emotional constraints of anxiety force a compromise. This compromise may take the form of infrequent or no visiting and *apparent* lack of concern for the hospitalised child. This provokes a judgement from professionals as the 'uncaring' parent. Graham reminds us, however, that: "... actions deemed irresponsible by professionals may be the only means by which mothers can act responsibly" (p.96). Mention has been made in an earlier section of the imbalance which frequently exists between the availability of resources and the appropriate uptake of these resources. The writer has observed numerous instances of such a dichotomy where parents who require psychosocial support during a child's hospitalisation, which on occasions includes basic practical help, are reluctant to express their need. Conversely this help has often been granted to the more articulate more assertive group of parents (personal observation during ward sister experience). In addressing this imbalance a careful assessment of the family is required. That this is done in a sensitive, non-judgemental and discrete way is crucial if the autonomy and self respect of the family is to remain intact. Graham (1984) in commenting on the attitude of the professionals to families who display a wide range of attitudes abilities and needs highlights the importance of the need for staff to respect the value systems of the families while addressing the implicit needs the health care situation brings.

Communication

Newson and Newson (1971), commenting on social class differences in parent-staff communication, summarised that since middle class mothers are better educated they are less likely to be intimidated by the "professional aura" which envelopes communication within the hospital milieu. Parents of higher social classes are able to articulate anxieties, which are in turn, less likely to be distorted by ignorance and superstition. This group is therefore more able to seek information and thus engage in active coping with the stress of the experience.

While it is the case that parents in middle class groups are more likely to share the same social group as hospital professionals, Stacey (1970), in a review of social class influences, highlighted studies which concluded that the higher the occupational status of the patients, the more likely they were to ask questions of their doctors, as opposed to waiting to be told by them (Cartwright, 1964; Skipper, 1966). Stacey further reported that this trend also applies to mothers obtaining information about their children in hospital. It is interesting to note that some of the 9% of mothers who reported that they had not received enough information in Stacey's study, did not in fact ask for it. In addition, mothers in the working class group received their information from nursing staff rather than from doctors. This suggests that mothers in working classes do not speak directly to the doctor in charge of their child's care as much as parents in other social groups. These differences between social classes cannot be explained in terms of a difference in the amount of importance attached to speaking to a doctor in charge, since, Stacey further reports that, when asked, 91% of both categories said it was important to do so.

Parent Expectations and Social Class.

Parent expectations of the experience are also influenced by social class. Expectations are a function of past experience, present needs and hopes for the future and are also related to the level of knowledge held by parents of the child's condition and the functioning of the organisation generally. Past experiences colour future expectations and this is evidenced in parents of all social groups. It has to be stated, however, that some parents either do not address their expectations at all, or if they do, they expect little apart from objective physical criteria (Harris, 1979; Alderson, 1990). Expectations are addressed in this study since it is considered important to know what is expected when asking questions about satisfaction with health care.

The convention of the World Health Organisation (1989), in addressing the rights of the

child toward the year 2000, made reference to the need to attend to issues of separation and family care during periods of health care treatment. Within this document, the right of parents to expect to be informed by professionals who have the ability to communicate effectively with them is re-stated. A parent requires to know how he/she can continue to function as an effective parent at a time of heightened anxiety and concern. Above all, a parent has the right to expect that she and her child will receive an excellence in clinical care delivered by a team who in turn expect parental involvement in this care, since an involved parent is an invaluable member of the therapeutic team. The 'Care by Parents' Initiative, recently set up in Wales (Cardiff, 1990) is a potential for progress as we envisage more parents becoming actively involved in their child's care. However, the writer offers an important caveat; that is, it is essential that such laudible schemes are driven by concern for the pscho-social well-being of the hospital family and not as a means of circumventing staff shortages brought about by current socio-political change. This important issue will be readdressed in the light of the findings of this study.

Numerous issues remain to be addressed by nurses and doctors. Many may find it disappointing in the 1990's to read of such imperfections in the system of care offered to parents and children as they prepare to enter hospital. The criticism is an indictment of the nature of the organisation and the services as a whole and the constraints under which individuals must operate. As Hall succinctly put it: "It is after all, another form of incompetence not to question established practices" (p. 728).

Maximising parental control within a health care setting is closely related to issues of parental competence. Much has been written about the effects of control over the events on subsequent levels of anxiety (Spielberger, 1972; La Montagne, 1984). An inter-relationship may then exist between parental control, parental anxiety and subsequently, the anxiety experienced by the child. If the emotion contagion theory is applied, then a clear possibility exists to circumvent parent and child anxiety by directly increasing the parents' level of competence in caring for her child in hospital. By and large, parents *are* the experts in relation to the behaviour and needs of their children, in the unfamiliar and at times confusing ward environment, parents need to be reassured of their competence to care for their own child. Nursing staff may inform their nursing care approaches by actively seeking the advice and involvement of the parent. The element of the present intervention which identifies the role of the parents in the preparation and care of the child addresses this need for maximising parental control over the events by providing preparation aimed at individual need for knowledge counselling and support.

The negative effects of the hospital experience have been a recurring thread throughout

this chapter. Attention is turning more to the possible beneficial effects of a 'well managed and controlled' stressful encounter in the life of the young child and, to the potential to build on strengths as a resource for future exposure to stress.

4 : 4 Hospitalisation, a Positive Experience for the Child?

The pathological orientation of much of the past research has failed to provide insight into how children can mature from the hospital experience. McGlowry (1988), asserts that the opportunity for individual growth, in spite of wide diversity, is a developmental question. Children may in Erikson's view, "transcend the period of crisis with further differentiation and growth" (1968). From an environmental viewpoint, insights into how the hospital can facilitate growth and recovery while mitigating distress, is also needed. Hospitalisation as a constructive learning experience has been little reviewed. Shore, Geiser and Woolman, (1965), suggest that physical and psychological benefit may result from admission to hospital. Vernon and his colleagues (1966) reports that the incidence of psychological benefit may be surprisingly high. Vernon looked at changes which indicate an improvement in the child's behaviour and found that 25% of the sample were reported by the parent to have made positive change following hospitalisation. On further analysis of the Vernon study, it is observed that most of the children showing positive change were from lower socio-economic groups. It can be argued that these children, because of prior life experiences were less dependent on a parent, or were more used to experiences of deprivation and more able to tolerate stress. In addition, Hall (1987) makes the pertinent point that children from lower social groups may find the hospital environment a "positive experience because of the level of care and relative comfort one usually associates with a children's ward" (p. 87). This position is fraught with many contradictions. As the literature on the children who are victims of social deprivation suggests, a child from a deprived home does not need the support of his parents less at a time of stress. On the contrary, this child may have a *greater need* for parental presence and familiarity if the hospital admission is not to be interpreted as the final abandonment.

The effects of illness and hospitalisation on subsequent responses to medical stressors has not been empirically investigated. Until such studies are conducted, the opportunities for growth presented to the hospitalised child can be assumed to be positive only insofar as parental perceptions of adaptive and positive behaviour change are reported. It seems important to begin to ask children if they gain from the experience. In terms of the child's conceptions of health and illness, post-hospital responses are reality based. An important limitation of the present studies is the failure to conduct longitudinal investigations

which would tap children's responses to medical and social stressors, thereby providing further empirical support of the effects of hospitalisation. In summary, a study of the responses to hospitalisation requires to assume a more consistent ecological orientation. For example, changing factors within the child; within the environment; and changing the attitudes and expectations of all who impinge on that experience is required if the negative aspects of hospital are to be minimised and the potential for the experience for growth realised.

4 : 5 The Role of the Sick Children's Nurse

The issues of concern to this chapter, open visiting, rooming-in provision for parents of sick children and preparation of parents and children for hospital admission, clearly have implications which extend beyond consideration of the family. They directly effect the role of the nurse and impinge on the way in which the medical role is executed. For example, the continued presence of parents in the ward reflects the application of the family care philosophy put forward by some paediatric hospitals (for example, RHSC Edinburgh) The continuous presence of mothers in the ward has the effect of bringing the nurses work to "front stage" (Goffman, 1971) and this may become a source of stress for the less experienced nurse. It also has to be recognised however that in practice, the relative shortage of nursing staff of a suitable degree of skill, tends to result in nurses accepting assistance from any quarter, for example, play leaders or parents. The impetus towards greater involvement by parents in for example care-by-parent units , popular in American Paediatric Units, (Cleary, 1984) and Cardiff, (1990) may be driven as much by cost and staffing considerations as from concern with the unity of the family and the distress experienced by children in hospital.

The role of the nurse is changing from an essentially task oriented role to one of addressing the needs of the individual family during medical treatments. Addressing the axiom that all those involved in health care are primarily concerned with the well-being of the client, Yarling and McElmerry (1986) suggest that the nurse, in promoting the well-being of the patient, do so free from "interference from doctors and bureaucrats" (p. 66). While accepting the changing paradigms on which current nursing practices are based, that is a greater awareness of the need to tailor nursing care towards the needs of the individual, rather than solely towards the treatment of the disease, Englehardt (1985), prefers to foster an awareness of the "in-between" position of the nurse which facilitates the unique contribution of the role. Bishop and Scudder (1990), in interpreting Englehardt's "in between" position of the nurse in health care suggests that there may be a dichotomy in which the nurse is caught between conflicting interests of the patient, the physician and

the organisation. This is, within the concept of the practical sense of caring, a contradiction. All involved in health care have the same ultimate goal, that is the well-being of the patient. The nurse is in a unique position to implement the essence of paediatric nursing, that is family centred care.

The commitment to parental support and education is a constant one and one which demands a high level of skill and expertise on the part of the nurse. Paediatric nurses have traditionally been accustomed to relating to parents of sick children. The emphasis has changed to one of teaching, supervising and supporting the mother (or father) in caring for their child while in hospital. Different skills and orientation are required. To be able to perform a procedure and to teach that procedure to others are two different competencies. Junior nurses in training have hitherto received the support required for that role from senior colleagues or from nurse teachers. The reform of nurse education (UKCC, 1986) changes the timing and nature of nurse learning experience. In effect, senior supervision is expected to be more consistent and the nurse is expected to be supernumerary during the early stages of preparation for practice, therefore is expected to be at a more senior stage of preparation prior to nursing sick children.

Reference was made earlier to the conflict which, on occasion, arises between parents and professionals. One of the rewards of paediatric nursing is the contact with the children. If this contact becomes mediated through the mother, some nurses may find they achieve a lower level of job satisfaction. Robinson and Thornes (1984), suggest that nurses are concerned with the devolution of 'basic' nursing and social contact to others, since they fear they may lose the pleasurable aspect of child care and be left only with the painful burden of technical nursing care. This concern is, in the writer's view, an exaggerated or inappropriate one. Nurses care for the individual family. The child in hospital is at the core of that caring and it is not possible within this individualised framework to fragment care to the level where the nurse no longer 'enjoys contact' with the child. Whatever care the child requires, whether recording vital signs, or tepid sponging a febrile child, the quality of human caring is in the nurse's ability to give herself to the situation. Extended parental involvement has in Halls' view implications for nursing autonomy. This view is critiqued on the grounds that professional autonomy in a health care setting can never be complete. The nurse is part of a team. A team which involves an array of professionals as well as the parent, all of whom have specific inter-dependent roles. The role of the nurse is an integral part of that team approach; the ultimate goal being that of delivering an excellence in patient care. The parents must also be viewed as part of the team. The converse then becomes the case, that is, the nurse who is able to view the parents as an

integral part of the team caring for the child, becomes more autonomous in executing her role.

Against a backdrop of cost containment and, on occasion, resistance to the active involvement of parents, there do exist some excellent examples of the nurses' role in relation to preparation of child and, to a lesser extent, of the parents.

Ferguson (1979), in an attempt to give individualised pre-admission care, set up a visiting programme whereby the researchers visited parent and child in their home. This home visit was reported to have a greater benefit to the mother, preparation was based on information giving. There are data to suggest that individualised nursing contact can influence children's response as well as parents' reactions. Skipper, Leonard and Rhymes (1968) reported on stress point preparation given by the nurses at selected points *during* hospitalisation. The findings suggest that mothers who received this approach were less intensely anxious than the control mothers. Research conducted in Britain and on the nurses' role in relation to preparation of child and parents is extremely sparse. While much can be learned from cross-cultural studies in relation to method and protocol, comparison of outcome must be tempered with an appraisal of the significant cultural differences which surround health care provision in Britain and (mainly) North America.

The potential for the development of the nurses' role in relation to a greater commitment to family preparation is considerable. For example, out-patient departments typically are run by a registered Sick Children's nurse. The opportunity to *begin* preparation in a more discriminating way exists. In addition, home care is a developing nursing role in relation to caring for the chronically ill sick child in the community. Potential also exists for expansion of this role to address preparation for the stress of hospitalisation.

An inter-disciplinary approach to preparation is considered beneficial (Rodin and Lawry, 1984). The nature of the objective stress must clearly influence the preparation strategy adopted. Medical colleagues are, on the whole, cognisant of the emotional needs of parents during events associated with health care treatments, for example, obtaining proxy consent for invasive treatments, or imparting negative outcomes of diagnostic procedures. Scope does exist for improvement however (Robinson, 1987; Roche and Stacey, 1990). Baroness Serota, in her foreword to Hailes-Took (1975) made the following pertinent points:

Changes in long-standing practices and attitudes underlying them cannot be achieved solely through encouragement by government, administrative re-organisation or even special appointments. They require above all a continuous process of learning for all concerned -- parents, staff, students in training, experienced practitioners, as well as the newly qualified.

With reference to the training of medical staff, Hardgrove and Dawson, (1972) believes that the problem lies at the selection stage:

A lot of people go into medicine interested only in the scientific aspects ... If we could present to the applicant a more realistic picture of his profession, we might get a more appropriate person, at least from the point of view of patient care ... in many ways nursing has done a better job at that kind of teaching. (p.54).

The main area for this improvement would seem to be the ability and motivation of medical staff to become more involved in the preparation of parents for hospitalisation of the child. It is currently common practice for parents to be told of the necessity of a particular treatment for their child by the consulting doctor in the outpatient department. The length of the consultation varies as does the opportunity for parents to think through the information given and subsequently ask pertinent questions. Preparation of parents requires more than information giving. Time and a commitment to listen and reinforce information and subsequent appraisals are necessary in the initial consultation period. This goal does seem a long way off but as Peterson et al,(1987) comment, it is only when parents become better informed of their rights within health care settings that they begin to question established practices. The potential benefit to the parent and child of a well-informed parent who has had the opportunity to work through his feelings, anxieties and expectations is considerable. Preparation for paediatric hospitalisation may then become more of a shared responsibility. The issue of proxy consent has been raised in an earlier section of this review. It is important that medical staff are cognisant of the intent of the process of consent by proxy if the anxiety experienced by some parents is to be identified. Parents' consent to medical procedures on their child respects the right of the rational person and acknowledges the right of the autonomous person. It is no less important when consent is sought on behalf of the child. Indeed, Alderson (1990) contends that attention to the sensitive issue of seeking the consent of the parents is a crucial preliminary step in planning health care treatments. The writer would also contend that such consent represents the first stage in the consent process. If this point is accepted by doctors and by nurses, the continued support which parents require as they work through the process of coming to terms with the planned treatments for their child, may be recognized.

In a review of the training of the Sick Children's Nurse, Hardy (1974) emphasises the

considerable demands placed on the learner.

"...She is expected in many instances to be a parent substitute as well as a nurse in training. She has to learn the skills of communicating with parents, understanding the reasons for their anxious and at times difficult behaviour, and of providing the right sort of support..." (p. 12)

Development of a scientific basis for nursing practice has been the goal of the profession for many years. The need for nursing theory as a foundation for nursing science and professional growth has been acknowledged by international writers (Benner, 1985; Melies, 1985; Parse, 1987; Benner and Wrubel, 1989). In relation to child health care, identification of the core issues of knowledge based on sound developmental principles and an awareness of the need to constantly update that knowledge forms the cornerstone of paediatric nurses' knowledge. From this basis, an understanding of the child's place within the family, the family in the community, and the role of the hospital within that community are central themes. Although numerous anecdotal reports have noted that an understanding of child growth and development is a pervasive concern for all aspects of nursing practice, little empirical evidence is available on nurses understanding and application of knowledge in this area (Howe, 1980, Waechter, Philips and Holiday, 1985). The utilisation of knowledge in nursing is in Gillies' (1990) view, a concern which crosses traditional disciplinary lines. In recent years researchers have focused their attention on the process whereby knowledge is applied to clinical practice. The dichotomy between knowledge and action is epitomised in the literature which addresses the role of the nurse within a paediatric context. Many writers (for example, Betz and Poster, 1984, Robinson, 1987 Orlick, 1988), identify a gulf between knowledge and application in their studies of paediatric nursing. The situation described by Robertson(1971) two decades ago strikes a familiar chord in the current literature :

...Not until systematic knowledge is built into the training can any advance be made. If doctors and nurses are to be more effective in looking after the mental health of young patients, their training must include the psychological development of children, coupled with adequate practical experience of normal healthy children - not only during training, but also at regular intervals thereafter to ensure that their norms of behaviour remain real.

(p.309).

A more enlightened attitude of current child care practices are largely applied to most paediatric units. However, feedback from parents, reported by the NAWCH, confirms that the application of knowledge to practice is by no means unanimously observed. The development of a substantive theory which can be applied to an understanding of child

health care has been tentatively reviewed (Julkunen, 1990). The basis of that theory being the commitment to transfer knowledge into practice and update that knowledge in the light of new developments in practice. Nursing is a dynamic discipline, one which requires to remain sensitive to the medical and psycho-social needs of the patients and their families, these needs continue to evolve. Nurses then have the commitment to validate and extend theories used to enable them to be effective tools in the pursuit of excellence in care.

4 : 6 Summary and Relevance of the Review to the Present Study

This review has centred on a selected review of the literature which is considered by the writer to be central to an understanding of the stress inherent in paediatric admission. The conclusions expressed in this summary are informed by the preceding literature review and are not only the opinions of the writer.

The stress and coping literature, while diverse and at times contradictory, has offered a focus for the study of stress and coping within a paediatric population. The cognitive transactional phenomenological model presented by Lazarus and Folkman (1984) identify the central areas of concern to this study. These are, the relationship between the personal meaning of the events to the child and his parents; the wide range of individual variables which influences their responses, as well as identification of the role of the environment in shaping these responses. The child entering a hospital ward for the first time, experiences a range of conflicting emotions. Excitement at the novelty in the situation is frequently tempered by a fear of the real or imagined threats which the typical hospital ward presents. The effect of past experiences on the child's interpretation of the events is considerable. The mediator of the impact of the perceptions is frequently the mother. It is therefore of importance to address the meaning of the event to the mother also. This is frequently confounded by factors which may transcend the immediate experience and be related also to anxiety about sibling care, visiting arrangements or work commitments outside the home. The extent of parental involvement in the child's care during the stress is an important issue. Some writers describe this involvement as a predictor of the child's emotional distress. However, the effect of parents presence must be studied in context. It is important to address the level of anxiety to which the parents are exposed before and during the child's admission. Some parents may find their concerns about the outcome of the treatments a crippling barrier to effective reassurance of the child. The impact of the emotion contagion theory is not questioned by the main body of the literature. There is a tendency to view emotion contagion as a process which flows from child-to parent-to- child, thus emotion contagion is viewed in the

literature as a bi-directional, reciprocal construct (Thompson, 1986).

The significance of differences in cognitive development in determining the responses of children within the medical setting address the child's perceptions of illness and medical treatments, as well as individual differences in attachment behaviour. In addition temperament has been identified as a useful predictor of response to stress. However, when a child is exposed to health care treatments, experiences normally outwith his frame of reference, the interaction of the many variables, for example, cognitive development, parental support, past experiences, resilience or protective mechanisms, as well as temperament influence in concert, his responses to the situation. The key issue to emerge from a review of the stress and coping literature is that of the personal meaning the encounter has for the individual child.

Preparation for the events takes account of the central variables. The salutary point was raised that preparation for paediatric hospitalisation in the 1990's is afforded a lower priority than was the case at the peak of the movement which addressed the psycho-social needs of the hospitalised child (post Platt 1960-1980). As a result of the decline of preparation programmes, few recent empirical studies are available. It would seem particularly relevant therefore that preparation programmes which are set up, should, as a crucial pre-requisite, take account of the limitations in resources by testing programmes which may be implemented within existing resources. Preparation implicitly involves the family, not simply the child undergoing the treatments. In this context, it is important to know the extent of the families needs (practical and emotional) and to address the individual strengths in efforts to circumvent the weaknesses.

The influence of social class on family adjustment is significant (Graham, 1984, McHaffie, 1988). It is not only the case that families from lower socio-economic groups may find the professional 'aura' of hospital intimidating, they are also, on occasions, burdened by concerns which interfere with their ability to cope effectively with the needs of their child in the medical setting. The range of coping behaviours adopted by parents and children in hospital is wide. The outcome of such coping approaches is variously effective. It is important however to accept the coping element in all the behaviours observed and avoid an observer definition of coping, which in the case of children in hospital, is less likely to be objective but to border on professional judgements about parental competence.

That some children ride the storm of the stressful encounter with *apparently* little or no negative effect is introduced by some of the reviews. It is important to restate however,

that most studies have followed children up (if at all) for a limited period after hospital admission. It remains an area of neglect in current empirical studies that the question of how children respond to subsequent medical and social stressors is not addressed. This is largely due to the real limitations of resources, which on the whole do not permit longer term follow up.

The equivocal nature of much of the literature serves to highlight the importance of the need for further empirical study in the area of child preparation for hospital. This preparation should be based on a knowledge of child development and an awareness of the goals of family centred care, is an important caveat in child care which is currently driven more by political definitions of health care, rather than an implementation of the philosophical principles of human caring (Putting Patients First - Secretaries of State, 1989).

The role of the nurse has been reviewed; it is however important to reiterate the present climate in nurse education; rapid change which as yet, is in the earliest stages of evaluation. The potential for development of the nurse's role in relation to the pre-hospital care of the family is great. This would require further empirical study in the light of the effect of the new 'philosophy for nursing practice' (UKCC 1986). Nurses are currently re-appraising the models upon which practice is based, this is moving towards a model of human caring which incorporates the needs of the hospitalised family.

The ultimate significance of this study lies in its potential for mitigating the effects of the stress inherent in planned paediatric hospitalisation for ear, nose and throat surgery. A large number of children within the age range studied are routinely exposed to this event. Although the nature of the objective stress may be considered less momentous than surgery associated with more severe, emotive and life threatening conditions, studies continue to highlight the importance of individual perception in interpreting the meaning of the experience for each family. Indeed, many studies fail to discriminate between the nature of the surgical procedure and the degree of parental anxiety prior to the event. (Fegley, 1988, Ferguson, 1979 Strachan, 1988). Bergman, (1975) supports this stance and views the issue as variations in degree and quantity rather than basic differences in quality and concludes that these differences relate to external physical realities rather than individual psychosocial realities. In the light of the well documented evidence of the effects of uncontrolled or unduly traumatic stresses, particularly during early childhood, (Quinton, Rutter, 1976) knowledge of intervention approaches aimed at minimising the impact of the stressful event, or enhancing the child's ability for realistic coping, will

ultimately contribute to the quality of care children have a right to receive and their parents expect. Despite empirical evidence supporting the need to care for Sick Children within a paediatric hospital cared for by Registered Sick Children's Nurses and paediatric surgeons and anaesthetists, health boards, in an attempt to centralise services are currently implementing major policy changes which undermines the philosophy of child health care provision within a paediatric hospital. This recent development, which is viewed as a major retrograde step by individual professionals involved in caring for Sick Children, effectively moves the over fives, who require ear, nose and throat surgery, to the facilities of a general hospital, to be accommodated within a system designed to meet the needs of the adult patient. The rationale for such a major step being the centralisation of services, greater efficiency and cost containment. In the light of these fundamental philosophical changes, the need for this research study to objectively assess preparation for paediatric hospitalisation is particularly topical and clearly necessary, as will be explored during the course of the literature review.

The preceding review facilitates the development of the theoretical framework which is considered to inform the issues raised in this study. Similarly, in the light of the review, it is now possible to operationalise stress and coping in the context of paediatric admission for surgical treatments. The research questions tentatively formulated in chapter 1. will then be refined.

4:7 THEORETICAL FRAMEWORK

The fruits of the preceding literature review have led the writer to the theoretical framework adopted for this study. The literature on theories of stress is extensive, their use in the present section is limited to the specific way in which they contribute to explanation and understanding of the area under investigation.

The elaboration of a framework for the analysis of responses and behaviours in health care settings is of particular value in integrating the diverse perspectives that arise from viewing behaviour through the separate conceptual windows of sociology, psychology and nursing and to suggest how concepts at one level, for example, the psychological, may be connected to, or nested within that of another, for example, nursing (Leventhal, 1990). The widely quoted adage of Kurt Lewin, "There is nothing so practical as a good theory", highlights the requirement that an effective theory will have great practical value .

The problem of stress and its measurement and management in medical, and in particular

in paediatric settings, presents in Leventhal's (1989) view a 'moving target'. This is especially evident in relation to the experiences of children and their parents during the process of paediatric hospitalisation. The events that generate stress and the techniques that can control it will almost certainly differ over settings and time within the same person. The writer is aware that no single theory can effectively communicate the diverse nature of the psychosocial issues to be addressed. The decision to embrace an eclectic approach is therefore made. The justification for the wide range of the literature reviewed specifically identifies the multifaceted determinants of children's and parent's responses within the medical setting.

Theories of stress, appraisal and coping, (Lazarus and Launier,1978, Lazarus and Folkman,1984-a - b.) underpin this study (and are discussed in Chapter 2). This cognitive, transactional phenomenological model of stress emphasises the relationship between the person and the environment and considers the individual characteristics of the person on the one hand and the environment on the other. This approach is considered particularly appropriate to the present study, given the range of variables which operate in relation to children entering hospital to undergo a planned surgical procedure. For example, age, gender, family characteristics as well as inter and intrapersonal factors and so on. In addition the influence of the environment is addressed as is the impact of the people who operate within it. All of these factors clearly impinge upon the meaning of the stress experience for the individual child and his family. Lazarus proposes that the variables and processes involved in the psychology of stress and stress control may be classified in three sets:

- i) The representation of the stress setting
- ii) Coping and or, procedures for responding to or managing the stress setting; and
- iii) The process of appraising, checking and updating the representation and coping processes as the individual acts to regulate the stress situation.

Lazarus (1984-a) further views these sets of variables as in a state of constant interaction or transaction, rather than acting in a rigid, linear order. In making the distinction between a framework and a theory, Leventhal, (1990) applies theory to more precise statements about the mechanisms that can be used to generate specific behavioural predications, such theories arise from pre-existing frameworks. Thus, establishing a structurally sound framework is a critical first step for the development of a sound theory. While the boundaries of these distinctions are open to debate, they are in Leventhal's view useful in clarifying the field and in helping to establish realistic expectations. More specifically, the distinctions help to emphasise the contention of many writers, (Lazarus,

1984, Leventhal, 1990) that it is currently premature to expect any single hypothetical and deductive theory to adequately analyse the enormous variety of problems arising in the medical setting. In order to use the framework and theory of Lazarus (1984) in relation to children in hospital, two key points require to be addressed.

The first is to define the goal of preparation, this is achieved in Chapter 6. The second point requires the inclusion in the model, the range of factors specified by the frame of reference and theory. It is quite inadequate, having defined a framework, to consider only a single issue within the total experience, for example, age of the child as a key variable. The total system must be considered when examining the outcome of preparatory procedures, particularly when comparing the outcome of differing approaches. The theoretical position offered by Lazarus, implicitly suggests a model for preparation includes a process of preparation for the *representation* of stressful procedures which focuses on the concrete and abstract aspects of the child's on-going experience, as the situational stressor unfolds.

The analysis will ask how the intervention affects the parents representation of the child's admission and subsequent treatment, how it interacts with the coping responses and the appraisal of outcomes.

4 : 8 Stress and Coping - Operationalised in context

Since the experiences of child and parent during paediatric hospitalisation are both problem, person and situation specific, attention must then focus on the unique manifestations of these experiences in the individual family. Addressing the diverse nature of person and situation factors requires consideration of the phenomenological perspective inherent in the theoretical formulations of Lazarus. The aim of phenomenology being the description of experience as it is lived by people, perception being our access to human experience. Phenomenological description is then the effective communication of insights into that experience (Oiler and Munhall, 1986).

Much of the psychological literature reinforces the clinical observation that children's manifest upset behaviours may not *alone* be an accurate assessment of their anxiety in a stressful situation (Izard, 1984, Kagan, 1983). This is important, as decisions regarding children's care needs in hospital have traditionally been based on observed behavioural manifestations, across age ranges, during the period of in-hospital care. Ferguson, (1979) in her study of preparation themes, suggests that in-hospital observations alone may not be an adequate basis for determining the individual response to hospitalisation. Behavioural manifestations appear to become more evident later, after transfer home to a psychologically 'safe' environment. It is therefore clear that an accurate evaluation of

children's responses can only be secured if stress is viewed as a process which unfolds across the duration of the experience and beyond, and this process is seen to be a multi-dimensional phenomena.

For the purpose of the present study, children's stress in the medical setting is operationalised in terms of overt or covert manifestations of upset. Overt distress, while easily identified, is less accurately attributed. For example, a crying child is in obvious distress and the nurse may make a reasonable assumption about the cause of such upset, for example, parent leaving, or, child undergoing medical and or nursing treatments. These treatments need not be invasive or considered 'painful' by the professionals, to be feared by the child. The unfamiliar nature of the situation and the events is considered stressful (Vernon, 1966). Identification of covert distress in the context of this study, requires attention to the work of the Robertsons (1970) and to the experience of the writer. Children who appear quietly resigned to their situation, may in fact may be more profoundly upset than their more vociferous counterparts (Rutter, 1981). It is therefore of importance to be aware of the subtle and complex ways in which children's distress may be manifest. These issues will be addressed in relation to the observation of children's responses during medical and nursing treatments.

Anxiety in the parents is operationalised in terms of parental expressions of feelings of anxiety which are perceived by the parent to be attributable to the child's admission process. Further discussion of this construct as it relates to this study is presented during discussion of the research instruments (chapter 5).

Describing how the variable under study is to be observed and measured requires addressing the concept of stress in context. The definition of stress adopted in the present study is that of Lazarus (1984) whose framework underpins the present study (chapter 2). Observation of the child's responses prior to knowledge about hospitalisation, that is, the child's typical response to any type of previous stress, affords baseline comparison between past and current responses. This is reported by the parents on the pre-admission questionnaire, received by all in the sample.

Responses at the point of and during admission are recorded in terms of the level of upset and co-operation with the necessary admission procedures, and are recorded on a five point scale ranging from calm and co-operative to extreme distress. Reaction to the first separation from mother is recorded along a similar continuum. Stress is thereby operationalised as responses in which the child's attempts to adapt to a new and potentially threatening environment gives rise to *overt* or *covert* changes in his behaviour

and demeanour, looking upset and distressed, or conversely quietly withdrawing and appearing apathetic and disinterested in his surroundings.

Both problem focused and emotion focused coping strategies are implicit in the nature of the experimental intervention. I have chosen this process oriented framework as an integrative tool because of its heuristic power and broad applicability to essential questions relating to stress and coping in health care settings. In applying the model to coping with stressors associated with child health care, I employ the emotion/problem focused dichotomy without further differentiating among the specific coping strategies subsumed within these categories, since this issue is addressed more fully in the literature review.

It is then clear that an accurate evaluation of children's responses to hospital can only be obtained if stress is viewed and measured as a multi-dimensional process, which unfolds over the course of the stressful experience and beyond. Subsequently, post outcome measures are operationalised in terms of parental expectations and perceived changes in the child's behaviour. These perceptions represent retrospective comparisons with pre-admission behaviours and demeanour and are clearly influenced by many variables. These will be addressed in a later section.

Satisfaction is operationalised in terms of parental expressions of being happy that the care and treatments received by the child was at least, of an acceptable standard. Also, the level of preparation and support given to the parents before, during and in preparation for coping after the event was at least at the level whereby parents felt they were receiving an appropriate standard of care. Definition of what represents 'acceptable care and appropriate standards' are discussed in relation to the role of the paediatric nurse within the specialist area studied, as well as the standards of care adopted by the hospital in general. It is important to comment that the Sick Children's Hospital in which the main study took place, set and maintain their own standards of Paediatric Nursing Care; these standards are constantly reviewed and updated in relation to changing health care needs, feedback from parents and changing paradigms within nursing.

Attention now turns to the details of the present investigation.

CHAPTER 5.

THE PRESENT STUDY

Methodological Considerations and a Discussion of Measurement Techniques; Description of Data Collection Methods.

5:1 THE RESEARCH STATEMENT and QUESTIONS.

This research seeks to study the experiences of the parent as well as the child during an encounter which is widely and empirically considered stressful. The prolific literature which addresses children's experiences during hospital admission have looked at the child in relation to his coping outcomes, or similarly, have studied parental coping with the acute events. Few studies have combined child and parent experiences within a single study (Peterson, 1989). This study also seeks to introduce an intervention based on the need to prepare the child and his parents for the events in a more discriminating manner. That is; the personal meaning of the encounter can never be predicted on the basis of identification of the key confounding variables alone.

Many studies have researched the effect of specific interventions, for example, filmed modeling (Melamed and Seigal, 1975), the use of puppet therapy (Cassel, 1969), or narrative hospital tours (Azarnoff, 1984). There have also been creative attempts at combined preparation approaches (Wolfer and Visintainer, 1979), including the use of cognitive coping strategies (Lamontagne, 1987). While accepting the value of the above approaches in terms of the individual contributions to the generation of theory and development of methods in the area, the central tenet of the present study lies in the need to address the individual needs of the child and parent as they are prepared for the experiences, both positive and negative, which constitute admission and surgical treatment. Indeed, it may be interpreted as an inherent contradiction to suggest that any specific approach to preparation is appropriate for the *individual child* and his parents. This fundamental issue will be addressed in a later section.

As outlined briefly in Chapter 1, the principal aims of this research are twofold. The first is to set up and subsequently assess the effect of an experimental approach to the preparation of children and their parents for planned paediatric admission to hospital

for ear, nose and throat surgery. The second aim is to elicit *information from parents* which are perceived by them to reflect their own and their child's experience during the total events which span preparation for, adjustment during and post hospital outcome of, paediatric hospitalisation for planned ear, nose and throat surgery. Indirect measures of child responses are therefore analysed in this study.

Focus on preparation for hospitalisation is justified on the basis that effective preparation is widely and empirically stated to mitigate the effects of the stress experience of the individual child and his parents. As has been reviewed, the present trend in health related research is to concentrate on those areas of study which are provider defined as being cost effective. This socio-political definition belies the need to address the needs of children in hospital, who in turn are not perceived as being a resource target group within existing political framework. The burden of proof for both the necessity and the effectiveness and cost effectiveness of a fresh approach to preparation for paediatric hospital admission clearly rests with the practitioner and the researcher. A comparison of preparation approaches therefore underpins this study.

The research questions tentatively reviewed in chapter 1, will now be refined.

The Research Questions.

- 1) Will the experimental intervention, based on identifying and meeting the needs of the individual child and his parents in relation to preparation for paediatric hospitalisation, influence the degree of upset displayed by the child, before admission and during his stay in hospital?
- 2) Will parental perceptions of their own anxiety and coping before the child's admission, be influenced by the nature of preparation received by child and parent?
- 3) Will the children who are reported by the parent to have found the experience of hospitalisation and surgery a positive one be more likely to have been prepared for the event, within the experimental treatment condition?
- 4) Will parental expressions of satisfaction with preparation, support and care throughout the child's hospital experience, be influenced by the approach to preparation? will parental responses which reflect their perceptions of the total experience be influenced by the nature of preparation?

- 5) Will the incidence of post-admission emotional and behaviour problems observed by the parent in the child's responses, be influenced by preparation for hospitalisation and surgery?

5 : 2 Significance of and Justification for the Study.

Admission to hospital for ear, nose and throat procedures represents the highest percentage of paediatric elective admissions to hospital each year within the National Health Service in Britain (Department of Health, 1991). In North America, ENT admissions are second only to circumcision in the frequency with which they are undertaken (American Health and Welfare - Annual Report, 1990). The average age range of children undergoing these procedures is 3 - 7 years. Despite recent concern expressed at the criteria selected for such surgical interventions, they remain commonly performed operations.

This research seeks to observe and assess the response to the stress inherent in admission and surgery, as it unfolds over the course of the experience. Also, the potential for positive benefits in terms of viewing the hospital experience as a learning one is addressed. Comparison of preparation approaches involving an experimental treatment condition and attention control group, as well as standard hospital preparation are studied. Parent and child responses are elicited, an opportunity for parental expressions of anxiety and satisfaction are an integral part of the research method. No studies read in the literature review have adopted this approach, although many have selected post responses or intra-hospital adjustment as measures of the child's coping responses. It is to a description of the research approach applied in this study that we now turn.

5 : 3 The Research Approach.

Introduction.

There is a general tendency in research methodology to place greater credence in generalisations from large scale surveys. This study chooses a quasi experimental design in tandem with a qualitative approach to eliciting child and parental experiences of paediatric hospital admission and surgery. Cicourel (1964) contrasts the richness of the latter with the objectivity of the former. Clearly, each method has it's own strengths and weaknesses. An eclectic strategy, precisely defined, avoids mono-method bias and goes some way towards satisfying the requirements of Denzin (1970) who highlights the concerns in relation to securing internal validity of qualitative data.

Many theoretical perspectives and methodologies derived from disciplines other than nursing, such as sociology, psychology and anthropology contribute to the theoretical foundation of nursing. However, a single perspective limits the study of many phenomena within complex and dynamic areas such as human health behaviour. The challenge which is currently being addressed by nurse researchers is to develop a methodology that integrates several of the existing research methods and conceptual frameworks to reflect the perspectives of nursing. This integrative approach is reflected *par excellence* in the methodology of triangulation. A triangulated study combines different theoretical perspectives, data sources, investigators or different methods. Triangulation, a term originally used to describe the military strategy of taking multiple reference points to locate an unknown position accurately, was first applied to research methodology by Fiske and Maddi, (1961). More recently, the term is used to refer to a particular study design that includes multiple methods. Denzin, (1970) defines triangulation as the combination of multiple methods in a study of the same phenomena, (that is the same empirical units) to depict more accurately the phenomena being investigated. The aim of triangulation therefore is to achieve results in which the variance obtained reflects the phenomenon being studied, rather than reflecting the method used to measure the phenomenon.

Because the demand for methodological diversity is based as much on researcher characteristics as on the phenomenon of interest, opportunities for exposure to a wide range of research methods are essential during the learning process of preparation for a research degree. The present study, having evolved through the progressive reduction of uncertainty, has reached the stage where addressing the intensely personal interactive process with the research data and having 'lived in' the data, it is now apparent that additional tools of analysis are required to do justice to the wealth of qualitative data gathered from the study. In particular avenues to explore explanation and contribute towards understanding of parental perceptions of parents' role in relation to identification of that which maximises parents' competence in a situation where they feel control to be compromised. Inherent in reflective thinking is the ultimate balance between cognitive and affective domains, the rational or analytical intuitive modes, the abstract and concrete levels of thinking and finally the deductive and inductive approaches.

The principal tools for the achievement of the above aims in the present study are the questionnaire and semi-structured interview. However it was also necessary to include other data collection techniques in order to adequately address the research questions and in particular to :-

1. Provide objective assessment of children's responses during pre-defined maximum stress points.
2. Maximise the validity of empirical evidence, by using a multi-method approach to data collection, mono-method bias is thus avoided.
3. Contribute towards the explanation and interpretation and subsequent understanding of information given.

This research sets out to establish whether a relationship exists between the independent variable, that is, the nature and level of preparation of children and their parents for paediatric hospitalisation and the dependent variable, which is the degree of stress experienced by the children and their parents before, during and after the child's admission to hospital for elective surgery. Acquiring scientific evidence requires making at least one comparison, (Campbell, Stanley, 1963.) The decision to select an experimental approach was made on the grounds of securing comparative data from the approaches to preparation studied. The principal sources of data for variables of interest in this study, lie in parent responses to questionnaires and to semi-structured interviews, self reports from parents, and in data recorded in observations of manifest upset and co-operation, by the nurse, doctor and anaesthetist.

The Experimental Design.

Justification for applying an experimental design to the present study is based on the degree of confidence in the genuineness and interpretability of relationships because they are observed under carefully controlled conditions. The term 'experiment' has a very precise and unambiguous meaning.

The use of an 'adequate' experimental design is selected also on the grounds of addressing the need to distinguish between what is thought to be true and what is known to be so. A quasi-experimental design is adopted for this study. This is necessary within the setting of children admitted for ENT procedures, since it is neither practical nor ethical to attempt 'pure' control within the framework of waiting lists and planned surgical treatments. However, the key elements of manipulation, randomisation and appropriate control are applied within the confines of the above limitations.

Many theoretical perspectives and methodologies derived from disciplines other than nursing, such as sociology, psychology anthropology contribute to the theoretical

foundation of nursing

The time honoured tradition of the scientific model clings tenaciously to research methodology, which seeks the 'logical' quantifiable approach to research. Although integration of approaches are now afforded a degree of respectability as they meet the requirements of scientific rigour, there remains a healthy suspicion of research approaches which are perceived to be less than 'scientific'.

The basis for the choice of a group experimental design, lies in the nature of the design and its scientific rigour. The underlying features depend on two groups being similar in all but one respect. If one group does significantly 'better' than the other, then the experimenter has garnered some support for the hypothesis that one treatment is better than another. However, as researchers accept the point with chagrin, it remains the case that rarely is a single experiment sufficient to establish beyond reasonable doubt that the 'better' treatment is also the treatment of choice. Although hypotheses can never be ultimately proved or disproved by scientific methods, the experimental approach offers the most convincing evidence concerning the *effects one variable can have on another*. Experiments then, come closer than any other type of research approach to meeting the criteria for *inferring* causal relationships. This is important in the present study for two principal reasons:

Firstly, it is important in clinical practice, to assess the effect of an experimental treatment by comparing the performance of the control group/s against that of the experimental group, if inferences about the efficacy of the new approach is to be made.

Secondly, as already alluded to above, research within the health care settings, where changing paradigms, priorities and policies are posing a challenge to existing practice, responding to that challenge involves presentation of rigorous research findings upon which present policy issues may be appraised in the light of empirical findings. This is likely to be particularly fruitful if changes may be implemented within existing resources.

The basic problem remains that of demonstrating a necessary relationship between intervention and outcome. The researcher however, must remain aware of the existence and importance of social and clinical significance when analysis seeks to report statistical significance (This point is addressed in chapter 9). In answer to the critique of tightly designed studies as being not only unnecessary in clinical practice, but by their complexity may actually interfere with practice, Yule and Hemsley, (1986) assert that as knowledge develops so will the nature of the experimental control be simplified. The authors argue strongly in defence of experimental design in clinical practice and contest that it is unethical not to attempt to evaluate therapeutic outcome experimentally. Certainly, if new approaches to clinical and psychological management are to avoid erroneous acclaim, then the researchers have a moral and ethical duty to monitor outcome in the most

systematic manner available to them.

With the goals of the experimental approach as they relate to the present study, thus defined, attention now turns to the means by which interpretation of the child and parent experience as they are lived, are analysed and understood.

5 : 4 Developments in theoretical interpretations during early stages of the analysis.

While the research questions imposed selection criteria on the overall research approach, the elaboration of a framework for the analysis of children's responses in the medical setting required that framework should be an integrative one. This integrative approach is particularly relevant to the preparation of children for hospital, since many variables at the sociological level, for example, parental motivation and ability to prepare the child is clearly influenced by the psychosocial factors which influence child and parents responses to stressful events.

The phenomenological perspective which contributes to the research approach selected in this study, is entirely consistent with the Stress, Appraisal and Coping paradigm which underpins the study. This paradigm, described by Lazarus (1984), views stress as a cognitive, transactional phenomenological model, which clearly requires an understanding of the meaning of the stress experience for the individual. Lazarus however describes his interpretation of phenomenology as inextricably linked to the concept of cognitive appraisal; that is, because cognitive appraisal rests on the individuals subjective interpretation of a transaction, it is phenomenological. The unfolding of the lived experience of parents and children during the child's admission and surgery during the early stages of analysis of qualitative data highlighted the need for the researcher to look beyond this inherently tautological conceptualisation of Lazarus, and seek to understand as well as explain the essence of child and parent experience. Given that the theoretical framework of stress and coping provides the pivotal dimension of the present study, the liberty to extend this framework is justified on the grounds that the researcher is 'listening to the data' and responding to the need to effect a comprehensive understanding as well as explanation of the content therein. This study therefore adopts an interpretive framework for analysis of child and parent responses as an appropriate response to the rich harvest of qualitative data gained from the respondents.

The relative merits of qualitative and quantitative research approaches have been debated extensively in the nursing literature. (Bargagliotti, 1982, Melies, 1985). The discussions surrounding the appropriate research approach for nursing has traditionally been ideological and philosophical. Gorenberg (1983), comments that the method debate should revolve around which method is more appropriate for nursing research. The

'either or debate' is not appropriate to the present study. When either approach is used alone, the data gathered may be artificially limited and incomplete, thereby limiting analysis and understanding. Open acceptance of contrasting paradigms preserves the advantages and unique perspectives of both approaches. The position adopted by Benner (1985) has much in common with that of the present writer:

...because a single paradigm in the human sciences claims that one single perspective provides the one explanatory vantage point and that all other paradigms are inferior or subordinate. One paradigm would provide a totalitarian explanatory system for all human behaviour and would assume one privileged position exists from which to view situations, capacities and problems of human beings. (p.12)

Whereas such a singular paradigm works in the natural sciences, because the background practices, skills and assumptions of the scientists are not issues for them, such a totalitarian stance is not only unattractive, it simply does not offer much in the way of explanation, prediction and understanding because the theories in human sciences must always presuppose common background meanings and practices. Extreme objectivity and subjectivity cannot capture the lived experience of health and illness because human beings are never fully objective or subjective; they exist in a network of concerns and relationships. A balance requires to be drawn between securing data that is 'known' to be objective; and attempts to capture the meaning of the experience as perceived by child and parent respondents. From early positivist beginnings, this study has developed a more qualitative approach as a result of the nature of the unfolding process of stress and coping observed across the course of the complex range of events which represent paediatric hospitalisation.

5:5 Discourse Analysis within a Hermeneutic Phenomenological Framework.

Benoliel, (1984) describes qualitative research as "modes of systematic enquiry concerned with understanding human beings and the nature of their transactions with themselves and with their surroundings" (p.5).

The present study integrates qualitative data with statistical data to inform and extend the understanding of the stress experience of parents and children in the study. It is important to emphasise that this combined approach is used to complement each data set and explicitly *not* to supplement either approach. Nursing is concerned with health promotion and the treatment of illness and disease. Health and illness are lived experiences and are accessed through perceptions, beliefs, skills, practices and expectations. Benner, (1985) highlights the problems implicit in being concerned with

both the phenomenal world, health and illness, and the biophysical world, disease, and asserts that these two levels of discourse call for different kinds of explanation and prediction . However, as Cassel(1982) succinctly stated:

...Therefore, so long as the mind/body dichotomy is accepted, suffering is either subjective and not truly real, not within medicines domain, or, identified exclusively with bodily pain and implicitly measurable. Not only is such an identification misleading and distorting, for it depersonalises the patient, but it becomes in itself a source of suffering. (p639.)

Benner (1985) asserts that in medicine and nursing we are only just beginning to learn to relegate our pre-occupation with quantitation to its proper place, and to also ask 'configurational' questions in more than one dimension.

The phenomenological perspective applied to the present study extends that of Lazarus and colleagues (1984) by seeking to interpret and understand the parts in relation to the whole and the whole in relation to the parts. This approach informs the understanding of child and parent responses during the period of heightened stress. In particular, an interpretive approach is considered to be of value in eliciting the 'hidden agenda' in the responses made by parents; which are interpreted to reflect their thoughts and feelings throughout the process of the child's admission. While the framework of Lazarus is of value in understanding and operationalising the stress responses and subsequent coping, the relationship between cognition and effect is not adequately addressed within this conceptual framework of Lazarus. The value of knowledge in nursing is, in part, determined by its relevance to and significance for an understanding of the human experience. That understanding requires the application of modes of enquiry that offer the freedom to explore the richness of this experience. Van Manen (1984) offers a succinct description of phenomenology, "...The study of the lifeworld, the world as we immediately experience it, rather than as we conceptualise, categorise or theorise about it" (p37).

The present study, with its positivist beginnings, has developed to the stage of seeking a mode of explanation and a level of understanding quite beyond that which the early conceptual framework envisaged. The data gathered from parents, which during the early stages of content analysis was shown to tap important areas relating to wider issues of family experience of hospital, requires the application of a more sensitive interpretive framework than that offered by the conceptual framework which informed the early thinking about the study. For that reason the qualitative data is analysed using discourse analysis within a hermeneutic phenomenological framework.

Hermeneutics, which allows for the study of the person in the situation, offers a way of studying the phenomenal realms of health and illness, and overcomes the problems of extreme subjectivity or objectivity. (Benner,1985) Hermeneutics has been used to understand everyday practices, meanings and knowledge embedded in skills, stress and coping (Benner, 1985). With this interpretive strategy, a means is provided for arriving at a deeper understanding of human existence through attention to the nature of language and meaning.

Hermeneutic phenomenology is holistic in that it seeks to study the person in the situation, rather than isolating situation and person variables and then attempting a reintegration. Hermeneutics as a system of interpretation is based in part, on the work of Ricoeur (1981). Ricoeur focused on textual interpretation as the defining element in hermeneutics. A text being defined as any discourse (conversation or speech) transcribed into written word. The purpose of hermeneutical description and explanation is to achieve understanding through interpretation of the phenomena under study (Allen, Jensen 1990).

Justification for an Interpretive approach applied to the analysis

The process of hermeneutic interpretation applied to the present study seeks to elucidate and make explicit our understanding of the behaviour, actions and reactions of child and parents as they are prepared for, experience and subsequently recover from the stressful events which accompany the child's admission, surgery and post-operative care. The process and spirit of analysis of the qualitative data in this study has much in common with the hermeneutic circle of inquiry (Heidegger, 1962) Interpretation proceeds in a circular manner with the projection of meanings and the anticipation of understanding. (Allen and Jensen, 1990), describe this process as one in which we understand something only in relation to its parts, and as we gain knowledge of a part, our understanding of the whole changes, a position which shares common ground with the theoretical interpretation of Ricoeur. This hermeneutic circle is a correlation between explanation and understanding and between understanding and explanation, and strives to uncover and explicate practical comprehension of the phenomenon, the interpretive account.

Interpretation and understanding are in a dynamic, dialectical, interactional relationship with one another. Interpretation reveals understanding, in turn understanding re-writes interpretation. As the part unravels the whole, the whole takes on a new meaning. Understanding then is an unfolding process, the stress and coping paradigm which underpins the study views the child and parent experience of stress as a similar process of

unfolding longitudinally across the course of the stressful experience. There is a merging of the theoretical concepts which inform and give direction to the present study, they are not viewed in isolation, but as an integrative whole with contributions to make at differing levels of analysis. A synthesis of theoretical positions will then evolve during the course of the final discussions. One needs to understand what one is trying to explain, understanding is achieved as a result of explanation. Rabinow and Sullivan, (1979) make the salient point, that to make a distinction between explanation and understanding is misleading. The interpretive method is the process whereby sense is made of the world, if all understanding is hermeneutical and our understanding is a historical process, (Reason and Rowan, 1981) then interpretation aims to bring to light an underlying sense of coherence.

The interpretative strategy used within the above framework is that of Thematic analysis. Common themes in the interviews are identified to present evidence to the reader of the emergent theme. Thematic analysis operates both as a discovery and a presentation strategy (Benner,1984). In interpretive research, unlike the grounded theory approach, the goal is not to extract theoretical terms or concepts at a higher level of abstraction. The goal is to discover meaning terms and to achieve understanding. These meaning terms will be exposed to discourse analysis with the aim of interpreting and understanding what the parents and children within the present study experience when they present the researcher with the privilege of sharing their accounts of the experience with them.

One of the most pervasive illusions which persist in the analysis of language is that we understand the meaning of a linguistic message solely on the basis of the words and structure of the sentence used to convey that message (Brown and Yule, 1983). This assumption does not address the complex cognitive and social phenomenon which is language.

Potter and Wetherall (1987), present a generic definition of discourse analysis as " All forms of spoken interaction, formal and informal and written texts of all kinds" (p.21). As a general introduction to the novice researcher, this definition, while all embracing, does little to focus the attention of the reader to any specific conditions, and therefore, value of discourse analysis. Parker, (1990) offers a sharper focus and describes discourse analysis as "A system of statements which constructs an object...essentially a contribution to language *in use* "(p190). The present study adopts a discourse analytical approach because of the potential to provide greater insights into the nature of actual meaning of language used and into the intricate relations between discourses and social situations. Also explication of the abstract structure of text and conversation is expected. Discourses do not simply

describe the social world, but also categorise it. They bring phenomena together, providing a framework for debating the value of individual realities.

When we discourse analyse a text we require to ask in what ways the discourse is attracting our attention, making us listen. The role the nurse has to adopt to 'hear' different messages from the same client or from other clients in the same setting requires to be addressed. Nurses are perceived by children and their parents as providers of care and often as mediators between the medical role, particularly in relation to communication, and the parents and child. The nurse in effect assumes a variety of roles in her day to day contact with families. The child and parents perception of role in any specific situation will clearly influence the nature of discourse. The language that people use structures role relationships to a varying degree. In his study which examined the relationship between linguistic processes, cognitive activities and social structures, Mehan, (1983) found that the status and authority given to a communication was determined by the use of professional language which conveyed the communication. The structure of the role relationships found embedded in the language used by the professionals, in turn, provided the authority for the claims or recommendations made (p.208). The purpose of employing discourse analysis to the present study may be summarised as 'clarity being the goal of communication'. Steps to elucidate the character and intent of language as expressed by parents of children undergoing surgery are enhanced by the application of the "system of statements" proposed by Parker and explored within a hermeneutic mode of inquiry. A comprehensive discussion of the approach to discourse analysis adopted in this study may be found in Parker, (1990).

The methods of data collection are now described.

5:6 Approaches to Data Collection

Data collection Methods.

The selection of appropriate data collection tools was particularly important in this study for a number of reasons. Extensive review of the literature indicates that little or no standardised measures exist which can be used to tap the stress experienced by children. There is therefore a relative dearth of appropriate measures of stress in children and stress in the hospitalised child in particular. Also, this study sought to examine the responses of parents as well as those of the children with the stated aim of assessing the nature of parental coping and adjustment prior to and during the child's admission. A variety of measures were investigated. These included physiological, behavioural and projective measures of the child's perception, of the parents perception of the child and of

an observer perception of stress behaviour in the child. The writer also considered the relationship between the crucial variables, for example, the nature of the illness, demographic measures, interpersonal factors and stress. Many measures were rejected because they were not reliable, or were too costly in terms of resources, including time. Many of the previously validated instruments were rejected on the grounds that their use could indeed generate stress in a paediatric population. (For example, indices of urinary excretion of cortisol and other physiological measures of adreno corticol activity). The taking of physiological data is in itself stressssful and often intrusive. Some measures cited in the literature were eliminated because of the likely infringement upon the physical or emotional integrity of the child which would in itself engender stress as well as raise problematic ethical issues.

The literature clearly shows that various measures of stress do not necessarily correlate, nor do they show changes for all children. Also it was important to avoid imposing additional demands on the nursing staff in relation to data collection. Since the measures required to be assessed by 'blind' observer ratings, reports of childrens responses were confined to those observations routinely carried out by the nursing staff, or requiring little additional nursing time and effort to complete.

A further criteria for selection of methods relates to the chronological age of the children in the sample. Pre-operational children are studied alongside children of school age. It was therefore important to standardise observational criteria, which should not be contingent upon specific input by the children themselves. As will be discussed in the directions for future study, this is seen as a limitation of the present study. Finally, most validation studies of stress have been completed with an adult population, very few have been additionally validated with children. All instruments are included in the appendices, and are now described in some detail.

5:7 The Research Instruments.

(a) The Pre-Admission Diary

This diary, developed by the researcher, was the fruit of a previous pilot study. (Strachan 1988)

Content validity was secured as a result of random testing of questions to the mothers of children attending a local nursery and primary classes 1-3. The diary is administered to the second control group only, with the stated aim of making a distinction between the effects of the experimental treatment and the effects of additional attention. Sent out to

thirty families to arrive one week before expected admission to hospital, the parents were asked to record on a day to day basis any changes noted in their child's behaviour or activities after he knew about the forthcoming hospital admission. This carried the implicit assumption that all parents would in fact tell their child about the imminent event, and that they would do so within one week prior to being admitted. As has been reviewed during the course of the early chapters, age is a central factor in the temporal issues surrounding preparation. The diaries are attractively presented and personalised. While it is accepted that the data contained within the diaries was not intended to be the subject of analysis *per se*, they serve the important purpose of providing a forum for discussion, constituting individual attention which is **specifically unrelated to preparation**. The intention being to discuss in general terms, the child's 'normal' responses at home. It is important to reiterate that the time given to control group ii is significantly less than that available to the families within the treatment group. In all respects the attention control group more closely resembles the standard control group. In essence, the diary in this study serves as a substitute for time and a control to maintain a neutrality of attention given. The discussions which centre on the content of the diaries, take place at a convenient time during the day of the child's admission, are kept brief and focused on the content only. A copy of this instrument is included in the appendix.

All groups receive the remaining five research instruments.

(b) The Pre-Admission Questionnaire.

Employing a pre-admission questionnaire enables base-line comparison to be made of the degree of change observed and reported in a particular behaviour. Also some element of common ground between pre- and -post- admission questions was built into the instruments to facilitate assessment of the degree to which the instruments are measuring the same thing. A measure of convergent validity is expected. Lazarus' emphasis on stress and coping as a process requires research into children's stress responses to observe the coping process as it unfolds over time. Many of the criticisms of approaches to assessing paediatric stress responses to hospitalisation identifies the limitations of research which looks at single events as indicators of a stress response. This questionnaire, developed by the researcher and drawing on many years of clinical and teaching experience within paediatrics generally as well as within the speciality, was modified as a result of a previous pilot study. (Strachan, 1988) The aim of the questionnaire is to address the research questions in relation to the child's usual responses to stressful events and also to elicit a profile of the behaviour and activities of the child in his day to day routine. Also, more specifically, the parents are asked to comment on how their child interpreted

episodes of potential stress in the recent past, for example, separation from parents, dental treatment, starting school and so on. The main part of the instrument asks parents to detail the child's response to news of the forthcoming hospital admission and to report any observed change in the child following this information. Closed questions are used to elicit factual data, more open questions are integrated to facilitate parental expression of qualitative areas of interest.

This first questionnaire is mailed out to each family to arrive after the information has been received from the ward and sufficient time allowed to assimilate this. Therefore, this questionnaire is mailed to arrive eight to ten days prior to expected admission. Parents are requested to bring it with them on the day of their child's admission when the researcher will look forward to meeting with them.

Instruments Used During In-Hospital Care

(a) The Admission Schedule.

On the whole, the research evidence shows that non-directive interview techniques are less successful than directive approaches. In the now classic Isle of Wight Study (Rutter et al 1970), four psychologists each interviewed nine sets of parents and then in a systematically balanced design, each re-interviewed three parents from each of the other interviewers one month later. It was found that systematic questioning of parents about their child's recent behaviour produced fuller information which was also more reliable, than did the parents spontaneous reports. (Graham and Rutter, 1968) However, the studies of Sackett (1979), while confirming the superiority of systematic questioning in yielding detailed information on a wide range of behaviours did not necessarily yield information relevant to an assessment of parental attitudes and feelings. The present study incorporates both open and closed questions where appropriate in order to address this issue. Kavale (1983), highlight the paradox implicit in the interview method. As one of the most widely used approaches to data collection within psychology, it is one of the methods least analysed within the theory of science. The mode of understanding applied in the present analysis and outlined above, requires attention to the following aspects:

The interview is centred on the interviewee's life-world; it seeks to understand the meaning of the phenomena in his life-world; it is qualitative, descriptive and specific. The interview is also free from presuppositions, focuses on particular themes and by virtue of the open nature of the questions, is open to ambiguities. Clearly such ambiguity is

minimised by effective piloting, since the present study incorporates structure with open questions appearing in the same instrument. This implies a strict separation of description and interpretation of the scientist and his subjects. A scientific method should result in objective reducible data, which then may be formalised in quantitative analysis. The qualitative research interview however, is based on meaning which rests on a subjective understanding. Notwithstanding the methodological pitfalls, this writer is aware of the need to secure scientific rigour throughout, while addressing the unique nature of the data collected in the situation of parents of children in hospital,

The interview is also an interpersonal interaction, the sensitivity of the interviewer is a significant factor. The respondent may find the interview a positive experience. These factors represent the main structure of the interview method, which is theme oriented, although in situations of heightened anxiety, the researcher is aware of the delicate balance between addressing the theme, the autonomy of the emerging text, and the particular needs of the person with whom she is exploring the theme. Newson and Newson (1976), who have successfully employed the interview to obtain a wealth of data in their longitudinal study of children in Nottingham, see the interview as an extended and subtly structured conversation: "Conversation is by far the most economical means in terms of time and effort, of arriving at a valid assessment of the situation". The writers further caution "...when using the interview as a scientific tool it is essential to ensure that the subject feels free to say anything he or she wishes" (p17).

This point is also emphasised by Bulmer, (1977) who suggests that people enjoy being interviewed, and by offering a programme of discussion and an assurance that information offered will not be challenged or resisted, self expression is facilitated to an unusual degree. Although the open question leads to greater difficulty when coding, allowing conversation to follow "it's own natural lines of development is inherently satisfying" (Newson 1976, p.22) The views offered by Benner and Wrubel, (1989), are of interest;

...Anyone who gives a sympathetic understanding to another person and creates a permissive non-judgemental atmosphere is likely to encourage cathartic release in the other person.

(p.39)

The sensitive nature of the interview is of particular concern within a health care setting when gaining insight into the topics of moment is the aim. This is particularly potent when inviting a respondent to share concerns and anxieties at a time of heightened stress and vulnerability. Mechanic (1978), asserts that there is probably no area of human behaviour more sensitive than maternal attitudes and practices during the course of

stressful events. The ethical implications are clearly important in that the availability of support and counselling required to be established before embarking upon the interviews.

Two approaches to the analysis of interview are described generally by Kavale (1983), that is the practical and theoretical approach. The researcher contends that the practical approach is a pre-condition to finally arriving at the theoretical approach which constitutes a methodological development, which the data in its transcribed, content analysed form, demands.

Reliability and Validity.

The problem of interviewer bias is addressed. Within a phenomenological understanding, it would appear an advantage that the interviews are conducted by the same interviewer, the requirement of standardised objectivity yields to the aim of individual sensitivity. The limitations of a single researcher conducting all interviews are that the opportunity for a broader, more richly nuanced and wider picture of the themes of research may be lost. This is balanced by the researcher 'being' in the research situation in its entirety, bringing the sum of experience and person to the situation.

Content and construct validity is secured as a result of pilot work. The pre-pilot work with parents of non-hospitalised children, which was conducted by the writer at the outset of the investigation, proved particularly valuable in shaping the research questions and probing areas of particular sensitivity. This was followed up by piloting in a hospitalised sample.

The problem of leading questions was overcome. In a focused interview what matters is to lead the interviewee towards certain themes in his experience of his life-world, but to specifically avoid leading him in the direction of expressing specific meanings about those themes. The aim being to work towards a reflective subjectivity with respect to the qualitative question-answer-interaction. The question of validity of the interpretive analysis will be addressed when child and parent responses are analysed in a later chapter.

The Admission schedule, with reference to the low return rate of pre-admission questionnaires gained in the pilot work, repeats all the key areas of interest elicited in this instrument. Therefore this instrument is seen as a continuation and development of that questionnaire. Developed by the researcher and drawing on professional experience as well as pre-pilot work conducted among mothers of children in the local primary school, where content and construct validity was enhanced, this semi structured interview is

conducted during the early stages of the child's admission procedures. The time of interview is held constant for all respondents, that is, to avoid contamination of parental responses by the events which occur after admission to the ward; all families are interviewed at a similar stage in the proceedings. Tape recordings and field notes are used to record the data from the interview. 'Time out' after each interview provides the researcher with the opportunity to record in the field notes, information that would not appear on tape, for example, the non-verbal communications of mother and child, the preferred activity of the child during the interview and the degree of ease with which the parents participated in the interview, particularly in relation to the child's presence or absence at this time. The interviews take place at the bedside where the child may either stay with parent/s or join with other children and playleader in the playroom. Most children combined both options and returned frequently to check up on the parents whereabouts.

The parent respondents were mainly mothers, although when accompanied by father also, most fathers were happy to leave the interview to the mother. It is important to establish one respondent at the outset, since continuity is essential when more than one method of data collection is required. There is of course, no methodological barrier to the parents acting together as respondents, as long as this is consistent. Two fathers acted as respondents, they were subsequently asked to complete the remaining instrument (PHBQ) after the child's transfer home.

The purpose of the admission schedule is to provide data from the psychological and sociological perspectives; that is to explore the routine day to day behaviours and activities of the child, to discover his responses to previous stressful events and to focus on issues related to the present admission. Opportunity for the parents to express their views about the child's adjustment to the event and any specific problems related to it, are incorporated. In addition, a profile of behaviours, similar to these asked on the post-hospital questionnaire are included to facilitate a base-line comparison. Parents are asked to comment on how they think their child accepted news of impending admission and to report on behaviour during the week prior to coming in. In addition, parents are asked if they would expect their child's behaviour to be different in any way both during the time in hospital and after transfer home. All ninety families co-operated fully with the content and spirit of the admission instrument.

(b) Parents Responses.

The GHQ.

An abbreviated form of the General Health Questionnaire (GHQ-12) (Goldberg and Williams, 1988), was employed to assess anxiety in parents within the recent past, that is within up to one week of the child's admission. The rationale for the use of the GHQ. in the present protocol is that it is an instrument designed to be useful in consulting session. The GHQ focuses on breaks in normal function, rather than longer term traits. Two major classes of phenomena are observed using this approach, both of which are highly relevant to assessment of parental adjustment to their child's admission to hospital.

- i) Inability to carry out one's normal function and
- ii) the appearance of new phenomena of a disturbing nature.

The instrument is sensitive to transient disorders thus longer term traits are not expected to influence the responses (Goldberg et al, 1984). The timing of administration during the present study is selected to coincide with peak stress points, identified as being after the child's admission and before surgery (Wolfer and Visintainer, 1979, Azarnoff, 1983).

Other empirically validated instruments considered included the various state/trait anxiety measures (Spielberger, 1972) These were found to have higher face validity, and the response categories are more easily understood than those of the GHQ. However, the latter instrument was chosen on the grounds of the reported higher concurrent validity. The original instrument was based on experience gained with the Cornell Medical Inventory. The two shorter versions of the GHQ which are currently used, are balanced for overall agreement set (GHQ-12 and 30.)

Each item consists of a question asking if the respondent has recently experienced a particular symptom, or item of behaviour on a scale ranging from 'less than usual' to 'much more than usual'. By avoiding a bimodal response scale the errors due to overall agreement set are reduced. Also the presence of an even number of response categories may eliminate the 'error of central tendency.' The GHQ does not make clinical diagnoses nor is it intended to measure long standing attributes of the respondents.

Scoring the GHQ-12.

The literature is equivocal on issues of scoring of the above instrument. The most straightforward way would be to assign a score weighted 0, 1, 2, and 3, to each column, that is, the Likert scoring, since there is no reason to suppose that much is gained by discriminating

between the first two columns other than by avoiding errors due to 'middle users' of response scales. Alternatively, the modified Likert may be used which assigns a 0 score to the 'better than before' and 'same as before' responses. This approach is adopted in the present study since the intention is to identify the parents who experience *change* in the days preceding their child's admission. The GHQ considers only the number of symptoms and is therefore an area measure. The Likert scoring is a composite measure encompassing both area and intensity. The GHQ method of scoring was rejected for the present study since it condenses a four way response scale to a bimodal one, with the potential loss of information. Since this study explicitly seeks to observe *degrees* of reported change a bimodal response is considered inappropriate. Goldberg and Williams, (1984) in response to this criticism of GHQ scoring point out that it is only marginally less efficient than the Likert approach, presumably because the nature of the information lost is not helpful from the 'case identification' point of view, which represents a major use of GHQ.

Parents are asked to complete the questionnaire in a calm and unhurried atmosphere at a point in admission proceedings when their child is being familiarised with the attractions of the playroom. Confidentiality is secured and the researcher is at hand if parents wish to discuss the questions.

Parent Responses

(c) The Interview.

Applied as a continuation of the above, parents responses were elicited using focused questions with the aim of exploring specific themes in relation to parents feelings and present attitudes in relation to the child's surgery.

Parents were also asked to express their feelings and attitudes to the present events. The open question was used to facilitate this aim. During this part of the data collection several ethical issues came to the fore. A few mothers were identified by the researcher to be in need of counselling help, particularly in relation to coming to terms with their decision to 'subject' the child to this surgery, a state which was due largely to expressed fear of anaesthesia. These mothers were subsequently seen (again) by the ward sister and arrangements were made for them to talk with the consultant anaesthetist. Although a small number, the decision was taken not to assign this group to a sub-group for the purpose of analysis, but simply to identify them as a group which required additional counselling help, since the majority of the sample expressed anxiety prior to the child's surgery. The difference in overt response may have been an indication of maternal personality, present anxieties, some of which may have been unrelated to the child's surgery, or an interaction

of many factors, for example, seeking reassurance of the wisdom of the decision made on behalf of the child, to proceed with surgery may be an important consideration. Clearly, analysis will take account of the group assignment of these parents and to their subsequent adjustment and that of their children. This interview subsequently formed an important part of the qualitative data which enables an interpretive approach to be adopted to analysis.

Observation of the Child's in-hospital responses.

(d) The Manifest upset and Co-operation scales. (Wolfer and Visintainer,1975,1979)

Observational sampling methods represents a mechanism for obtaining representative examples of the behaviour being observed, without having to observe the entire event. Event sampling will select integral behaviours during the events, which are pre-selected to represent maximum stress points during the child's hospital experience. The rating scale tool requires the observer to rate some phenomenon in terms of points along a descriptive continuum. Ratings can then be quantified during analysis of the observational data. The decision to involve independent observer ratings was taken on the basis of exerting some control over correlated measurement bias. The observers conducting the ratings of the two outcome measures of children's in-patient adjustment are experienced staff nurses who are not involved in the experimental treatment. A blind procedure is therefore possible. Direct observation is made by staff nurses who are experienced in the care of the sick child and who have had a minimum of six months experience within the speciality. The staff remain 'blind' to the treatment conditions throughout. Inter observer reliability checks made prior to the main data collection reached 96%, the variance being due to observation of the manifest upset of the younger children, mainly during first parental absence. Further checks conducted during the study continued to show this high level of reliability.

Two measures of the child's emotional adjustment and co-operation are made during the period of in-hospital care. Soundly validated scales are chosen and found to be appropriate in contributing to addressing the research questions. The scales developed by Wolfer and Visintainer, (1975,1979), although validated mainly in North America, requires attention to the cultural and administrative differences between American and British health care provision. The present study, as a result of the pilot work, incorporates observation of upset and co-operation in relation to paediatric research within a National Health Service setting in Britain.

i) The Manifest Upset scale:

A five point scale designed to reflect the emotional state of the child at a given point, primarily in terms of verbal and non-verbal expressions of fear, anxiety or anger (Wolfer and Visintainer, 1979, Mahaffy, 1965, Skipper and Leonard, 1968, Azarnoff, 1984). It is important to reiterate that a calm but awake child may be in one of several postures and exhibit varying degrees of inquisitiveness and loquacity, but with no indication of anxiety. The present study is based on methods which include the hypotheses that anxiety is reflected in types of behaviour which are observable and measurable in quantitative terms. It is also clear that anxiety may not necessarily be discernible by the methods employed in this study. An awake but calm child is not necessarily devoid of all anxiety; neither is a sleeping child. Furthermore all children who are crying do not necessarily experience the same depths of despair, nor the same reasons for, or types of anxiety.

Despite these limitations, the use of behaviour as an index does provide empirical data which cannot be obtained readily under clinical conditions by other means. In an attempt to address further, the variability of children's responses, the present writer includes an additional category on both the manifest upset and co-operation scales. This category is intended to be used for responses which are considered by experienced nurse observers, to be outwith those presented on the scales. The inclusion of an additional category was based on many years clinical experience with children in hospital as well as a knowledge of healthy responses by children to stressful events. Preparation of observers in the use of the scales also included full discussion on the use of non-category responses, followed by clinical inter-observer reliability studies within a clinical setting, which included non-study samples.

Scoring the Manifest Upset Scale.

A rating of 1- indicates little or no fear or anxiety, calm appearance, no crying or other verbal upset.

A rating of 2- indicates some crying and or verbal protest, the child can be comforted by nurse or mother and settles fairly quickly.

A rating of 3- indicates a crying child, more difficult to comfort, requiring continued support from mother or from nurse.

A rating of 4- indicates a very distressed child, protesting loudly, very difficult to comfort, unable to accept reassurance.

A rating of 5- indicates extreme emotional distress, an agitated child who may be crying,

or screaming. Requires constant nursing or parental presence, very difficult to comfort.

Non category responses - specified by the observer and scored in relation to the experience of the observer and the other measures relating to the same child.

The times and events selected are :

- At the point of admission to the ward, when child and parents are welcomed by the admitting nurse, who then proceeds to conduct child and parents to the bed/cot area and proceed with nursing observations, for example recording temperature, weighing the child, securing an identity bracelet, usually on the wrist. Other routine observations prior to surgery, which include, testing urine, observing the child's nutritional state, condition of skin and so on, take place during this time, at a pace set by the individual child with flexibility being an essential component of the procedures. During this time the nurse discusses the forthcoming events in terms of the practical aspects of parental involvement in care, and describes the plan of treatment for the individual child . No aspects of the above admission procedures are considered to be intrusive or to cause physical discomfort.

- First parental absence , either for a short period, for example, parent remaining in the hospital environment, but leaving the ward for a break, or for a longer period, parent leaving the child for the night. The child's degree and duration of upset is recorded, covert as well as manifest signs of distress are included in the assessment, as an 'additional category response'. Parents are explicitly asked to tell the child exactly where they will be and when they will return. This has been integrated into ward policy in response to the many episodes of inconsolable behaviours experienced by children who had been misinformed by their parents, who in turn were motivated by misguided ideas of avoiding upsetting the child.

- First night settling, either in the presence of parents or being settled by nurse. The child's responses to being settled for the night in a hospital bed with other children in close proximity, being introduced to the night staff as the day staff go off duty. Television and radio are switched off at a prescribed time, although older children may continue to use the in-hospital radio facility 'radio lollipop' with the use of ear phones.

- Transfer to the operating theatre. A specific event which involves nurse and child only, parents being asked to leave the ward before the operating list begins. The child is carried in to the theatre by the nurse who accompanies him to the preparation room. This room is simply a short stay waiting area and in the absence of a anaesthetic room serves the

purpose of efficient transfer of children across the corridor to theatre. Children are never left alone in this area, a video-tape recording, usually of cartoon characters, or a quiet story read by the nurse in charge is intended as a distraction. Nurses record the child's responses to this period in its entirety, that is from the point of leaving the bed/cot in the ward area, to the point of reception in the operating theatre.

- Return to the ward post-operatively. The child's ability to settle in the immediate post-operative period as an indication of upset is recorded. The safe return of the child to his/her bed requires concentrated skill and expertise of the doctor and qualified nursing staff. It is a time of intense activity, which frequently requires the use of technical equipment to secure a clear airway while avoiding disturbing the now raw tonsillar bed, a practice that would encourage bleeding. Children wake up quickly from this short anaesthetic and are often very frightened and in some discomfort. Parents are generally asked to return to the ward only when all children scheduled for the same operation, have returned from theatre. Therefore settling within this period is usually in the absence of mother. Invariably, 'Mummy' is the first word the children utter when they regain consciousness.

Event sampling addresses the need for child co-operation during potentially stressful medical and nursing procedures, for example, administration of premedication drugs or induction of anaesthesia. Although the literature varies the times and events sampled to represent maximum relevance to individual settings, the studies unanimously support the view that observation of co-operation and upset are indicative of behavioural upset. Review of the developmental literature however, would suggest that this may not consistently be the case. Variables other than those operating during the period of observation may serve as a powerful influence on the child's adjustment to them, for example, the extent of parental anxiety, pre-hospital adjustment and so on. For this reason, these variables are addressed and mono-method assessment of behavioural upset is avoided by using also, the criteria of post-hospital adjustment and change, as well as assessment of upset and co-operation by multiple observers.

ii) The co-operation scales.

Again a five point scale designed to indicate the degree of co-operation with specific procedures. Co-operation is defined by behaviours which facilitate the procedure to the benefit of the child as well as to the care-giver in terms of the time and effort taken to carry it through. Ineffective or negative responses are those behaviours which disrupt or

hamper the activity, thus increasing the level of stress to which the child is exposed. The inter-relationship of manifest upset and co-operation is clearly apparent. The scales indicate the following:-

A score of 1 - indicates complete co-operation, this may include active participation in and assistance with the procedure.

A score of 2 - suggests mild or initial resistance, or passive participation without assistance.

A score of 3 - indicates initial resistance, crying, but can be comforted and encouraged to co-operate.

A score of 4 - indicates an upset crying child who is resistant to nursing or medical treatments, requires considerable nursing or parental support and comfort.

A score of 5 - indicates extreme resistance, strong avoidance. The child is unable to respond to explanations or persuasions. The procedure was either abandoned, or carried out only when the child was restrained.

Non-category response, assessed, described and scored by the observer.

The following events are assessed:

- The admission examination, conducted by doctor in the presence of parent/s. This examination involves necessary co-operation by the child, for example, throat and ear examination, and examination of the child's chest. The time is also used to elicit recent medical details of the child's health, to ascertain family history and any medical condition which may potentially interfere with or complicate recovery from the present operation. The opportunity for parents to ask further information is available, but is often contingent on the level of child co-operation and upset. The above examination does not involve any degree of physical discomfort for the co-operative child. If the child is unable to co-operate the examination is frequently left until he/she has settled into the ward.

- Co-operation with pre-operative medication. This involves the administration, by a Registered Sick Children's Nurse (RSCN), of an oral sedative in preparation for anaesthetic. The tablet is crushed and given with a few drops of orange juice only, since the child must fast prior to general anaesthesia. The decision to use oral as opposed to intramuscular injection of pre-medication is a unit policy and based on the desire to avoid painful or threatening medical procedures wherever possible. However, it is clear that some children have great difficulty swallowing the oral preparation.

- Co-operation with induction of anaesthesia. All children receive a brief tour of the operating theatre on the afternoon of admission to the ward. They are encouraged to handle the equipment, for example the mask. All instruments are kept out of sight, since the child will not actually see them during the operation. Similarly, the child has previously met the anaesthetist, although on that occasion the doctor was not dressed in theatre clothes. The child is generally received by the anaesthetist and asked to co-operate with induction, the procedure being explained. Induction is very quick, children who can, are asked to start counting to ten, they are generally asleep by the count of three. Younger children are asked to describe the colourful mural on the ceiling of the theatre. The anaesthetist records the level of co-operation the research scale being securely attached to the anaesthetic form.

- Subsequent post-operative settling is recorded by the nurse observer. Co-operation with necessary immediate post-operative nursing care, for example, safe positioning of the child, attending to personal and oral hygiene, recording vital signs, (pulse rate is recorded at fifteen minute intervals for the first two hours, half-hourly for four hours and hourly during the first post-operative night) and changing the child from theatre attire into his or her own clothes. It is essential that post - operative tonsillectomy children are kept calm and quiet in the few hours after surgery. Nurse observers therefore record whether the child required sedation, or settled without it. Parents are generally with the child at the end of these procedures. Parents are encouraged to hold and comfort their child in their own way, most equipment is removed before parents rejoin their child.

- Co-operation with and ease of post-operative fluid intake. It is expected that, following tonsillectomy, the child will experience some degree of discomfort. However, clinical observation during time as a ward sister within the speciality showed that younger children tended to have less difficulty with fluid intake after surgery, than school age children appeared to experience. There are many hypothesised developmental reasons for this observation. The role of expectation of pain and the perceived threat of any activity which would constitute discomfort, are described as being significant in the older child's perception of post-operative pain.

Emphasis by nursing staff to parents and subsequent preparation of children by parents, on the importance of drinking and eating after tonsillectomy may well produce undue anxiety in the mother and child. Older children accept that they cannot be allowed home until they are eating and drinking normally. It is hypothesised that anxiety in relation to post-operative drinking actually perpetuates the perceived difficulties. Co-operation is recorded by nurse observers in relation to the amount of encouragement required by the

child and the apparent difficulty he has in drinking post-operatively. A mild analgesia (Paracetamol elixer) is administered to each child prior to his first drink, this is repeated four hourly during waking hours for the first day following surgery.

- Acceptance of and ease of eating first post-operative meal. The importance of using the oral muscles and those of swallowing is well documented in the accounts of the post-operative nursing care of children who undergo tonsillectomy (Cowan,1987). Emphasis on eating four hours after surgery is seen as a preventative measure. Infection, which may give rise to secondary haemorrhage is a complication which is known to be more prevalent in children who do not eat well. Nursing staff within the speciality are expert in providing the child with an acceptable diet, while encouraging him to use the muscles of mastication and chew his food. Co-operation is assessed in relation to the time taken by the individual child to complete a simple meal, the amount of discomfort associated with it and the level of resistance to the process displayed by the child.

- First post-operative voiding is recorded in relation to when the child voided following surgery. Azarnoff (1984) in supporting the inclusion of this observation, found that children who were particularly anxious during the pre-operative period took longer to void post-operatively. In the present study, this variable is considered alongside that of co-operation with first fluid intake.

As one indication of the construct validity of these measures, all had been used in three studies conducted by Wolfer et al (1975, 1979,). In addition, Azarnoff, (1984) reported 'adequate' reliability in the Manifest upset and Co-operation scales in her study of children's responses to pain. Fegley, (1988) also found the scales of value in monitoring the effect of instruction versus non instruction prior to cardiac catheterisation in a child sample. Mahaffy (1965) in his study on surgical patients found the overlap between the scales of value in reducing observer bias and in securing inter-rater reliability. All measures adopted in the present study have been validated and found to have a high level of reliability in the present (1990) and a previous pilot study, both conducted within clinical settings in Britain (Strachan, 1988).

Post Hospital Instruments.

(a) The Post Hospital Behaviour Questionnaire.

Developed by Vernon, Foley and Schulman,(1966), the post-hospital behaviour questionnaire (PHBQ) was collated from six earlier studies which looked at the indicators of psychological upset in children following a period of hospitalisation (for example, Jessner and Blom, 1952.) The criteria for selection in the final questionnaire being the repeated appearance of a symptom in more than two of the studies. While most investigators have relied primarily on the incidence or change of incidence of various 'symptoms' for measures of post-hospital reactions, for example, sleep disturbances, regressive behaviours and so on, the relationship between the symptoms has largely been ignored. The Vernon (1966) study explored the relationship among symptoms by factor analysis in order to isolate patterns of response and describe the dimensions of these responses which resulted from a factor analysis of a questionnaire dealing with changes in behaviour following hospitalisation.

The PHBQ. attempts to itemise observations that have been made in earlier studies on the post-hospital behaviour of children. The twenty eight item instrument used in the Vernon study focused on behavioural indicators of stress, and was sent to parents of 800 children, six days following transfer home after elective surgical treatments. Less than half the questionnaires were returned, (327) representing subjects from 18 months to 16 years of age. Parents were asked to compare their child's post hospital behaviour with their pre-hospital demeanour. Validity of the questionnaire was established in an independent study by Davenport and Werry (1979), who compared the total scores on the questions with independent ratings of non-directive interviews by a child psychiatrist. The above instrument, although subjected some criticism, has been widely used because it was developed specifically for use with hospitalised children. Few other questionnaires are currently developed which attempt to measure stress in children and those that do, depend on self report by the child and /or are very age specific (Spielberger, 1971, Melamed, 1980)

Given the developmental variables applicable to the present study, it was necessary to obtain a measure which could be used across the 3-7year age range. The PHBQ. represents such a measure. In addition, it has been suggested in the literature, (Vernon, 1966; Davenport et.al.1979; Ferguson, 1979; Peterson, 1989), that the practice of placing children into one of only two categories when assessing post-hospital adjustment, namely those children who are 'worse' and those showing 'no change', is misleading, since this type of

analysis fails to reveal those children who may have improved after hospitalisation. Much of the relevant research is aimed at detecting upset which may be attributed to a stay in hospital. In a re-analysis of the original data, Vernon, (op cit) found that 25% of the sample actually benefited from hospital admission. Clearly this has to be interpreted in the light of a knowledge of demographic, inter and intrapersonal factors of the sample. However, in a similar study, Ferguson, (1979) demonstrated a significant improvement in behaviour among children of lower socio-economic groups following a short stay in hospital. The studies on vulnerability and protective mechanisms, reviewed in previous sections, casts some light on this finding, although knowledge of the child's exposure to previous stresses is important. The studies by Rutter, (1987, 1989) support the 'steeling' effects of coping with a previous stressor, when attempting to predict the child's subsequent adjustment.

The main criticisms of the PHBQ require to be fully addressed. The major thrust of the critique relates to the emphasis on parental perceptions of the child's behaviour and is therefore open to bias, parents being subjective in their interpretation. Also, no mention is made in the Vernon study of whether the questions were directed to one or both parents. As has been seen in this pilot study consistency of respondent is an important issue. Azarnoff (1981) reported considerable discrepancy between the fathers perception of the child's behaviour and that of the mother. Experience in clinical practice leads the present writer to suggest that the parents are looking to differing criteria on which to base their assessment. Clearly parents perceptions of their child's behaviour is influenced by their expectations within varying situations and within differing social roles. The role of the parent is gender oriented, the sex of the child also influences implementation of that role. The present study secures consistency of parental response at the outset, thus addressing this potential threat to reliability.

Also, Vernon used the questionnaire, only as a post measure, thus depending on the parents having an accurate retrospective recollection of the child's pre-hospital norm. This in Brain and McLay's (1968) view is likely to produce either an exaggerated account of the child's problems since return home, or alternatively an overly optimistic picture of how well the child handled the situation. The present study includes the PHBQ items in the Admission Schedule in order to achieve a base-line comparison and to effect a degree of objectivity in the post-hospital responses. A further criticism of the original instrument is that all items are directed towards the negative pole, thus in agreeing with the statement, a parent is agreeing that the child is exhibiting a stressful behaviour. The overall impression of the questionnaire therefore seems 'loaded' and may well lead to response set on the part of parents. Although the inclusion of some loaded items is

appropriate in this type of study, (Seaman, 1987, Azarnoff, 1984), it is preferable to balance the loadings between positive and negative poles. This is achieved in the present study by keeping negatively phrased items to a minimum. Finally, the reported reliability and validity of the questionnaire seems somewhat weak. The validity procedures of the Vernon PHBQ make no effort to compare parental perception of the child's stress with other measures of in-hospital adjustment. As a result, the validity taps the parents perceptions, but we do not know whether it accurately indicates that the child is indeed stressed. The present study addresses this criticism by employing multiple observers. The decision to use the PHBQ in the present study was taken on the basis of further validation of the instrument following modification in several North American studies. (Wolfer and Visintainer, 1979, Davenport and Werry,1979,Azarnoff,1984).

In summary, the present study incorporates the following changes to the original instrument as validated in these three studies.

- Measures in addition to the Vernon items are used in an attempt to operationalise stress in hospitalised children undergoing a range of potentially stressful procedures and experiencing a wide array of potentially threatening events.

- Employing pre-admission and post-admission data within the same study facilitates assessment of the degree to which the instruments are measuring the same thing, a degree of convergent validity is expected. This approach also circumvents the limitation of the Vernon instrument in that it does not depend entirely on parental perception of change.

- The response categories applied by Azarnoff (1984) are more appropriate to this study. The responses are grouped into four categories:-

- i) Those children showing *improvement* on the variable
- ii) Those children perceived as being "same as before"
- iii) Children showing some negative change in behaviour
- iv) Children showing marked deterioration in behaviour

Timing of the post measure is the subject of much contradictory debate (Rose, 1972, Peterson and Shigotomi 1982). If the measurements are attempted too soon following transfer home, children who are still experiencing physical discomfort would be expected to be showing more negative behaviours. Conversely, a longer period post-admission is likely to increase the attrition rate, or at best decrease conscientious completion of the questionnaire. A balance adopted for the present study, involves waiting until the child has settled into a

normal routine, is likely to have recovered physically from the procedures and be back at school or nursery. The PHBQ is therefore sent out to arrive 12 to 14 days after the child has returned home. All parents agreed to the researcher sending a postcard or telephoning prior to mailing the final questionnaire.

(b) Parents outcome measures.

The present study also includes parental satisfaction questionnaire as an integral part of the post hospital outcome measures. Methodological issues required careful consideration when developing an appropriate tool. Many of the studies reviewed which dealt with satisfaction, differed in their aims and method by which data were collected. The purpose of the present study is also to ascertain parent opinion in relation to satisfaction with care received before, during and after the child's hospital experience. The term 'care received' is deliberately open ended to include and invite comments pertaining to medical, nursing and other related aspects of care within a paediatric setting.

As yet, no method has been developed for measuring client satisfaction which could be adopted as a standard to allow comparisons across studies to be made. The issue is further confounded by the fact that parental satisfaction represents indirect measures of quality and standards of care when related to the child who is rarely asked what he felt was good or not so good about the care he received while in hospital. It is the writer's view that children are most discriminating and valuable data could be obtained by asking their views. The barriers to this approach, which apply to the present study is the accessibility of the child after he returns home, in order to objectively obtain the child's opinions. Further personal contact would be required at an appropriate time after the hospitalisation. For the purpose of the present study, satisfaction is defined as a general expression of feeling content and happy with the process and outcome of care received by the child throughout the experience, as well as a similar expression in relation to parental support, preparation and care. A situation where, expectations if consciously held, were met. Satisfaction reflects attention to the individual needs of child and parent in a stressful encounter.

Two basic ways of acquiring data on client satisfaction are described in the literature. Respondents are asked to talk about or comment on the services they have received, or, they are asked to respond to a series of direct questions about their satisfaction with aspects of these services. The now classic study by Locker and Dunt (1978) cites multifactorial reasons for the increase in importance of assessing client satisfaction. A central reason which in the 1990's is particularly topical, relates to the interest of central

government in the use of evaluative research in the formation of social and health care policy. Cost effectiveness is synonymously linked to efficiency and effective health care provision. The emergence of the medical and nursing audit, further formalise evaluative approaches, at a time when as a profession, we should be asking the client to help shape his own health care. Carstairs, (1968) highlighted the importance of asking the questions in an appropriate way. She found that unstructured questions provided different results. For example, in the study by Cartwright, which sampled client views on "how the General Practitioner explained things to them", 75% of respondents, when asked directly, reported that their doctor was good at explaining things to them. However, in response to an open question, only 4% mentioned this as a quality appreciated in their doctor. The discrepancy may be due to the fact that individuals will report satisfaction or dissatisfaction with particular aspects of care when asked directly, but may not give sufficient priority to these aspects to merit mention in response to an open ended question. It seems likely that direct questions act as probes to elicit dissatisfaction with aspects of care which have less impact on the respondents than those mentioned in response to open ended questions.

The concurrent use of both methods is adopted in the present study in an attempt to provide a more comprehensive picture of parental satisfaction in an attempt to answer the research questions. The further value of eliciting parental satisfaction in relation to paediatric health care are as follows:

- As evaluations of the perceived quality of care.
- As retrospective parental assessment on behalf of the child
- As outcome measures
- As indicators of which aspects of service require to be changed to improve parent satisfaction.

The problem of achieving a measure of validity in satisfaction studies has been addressed. (Lebow, 1978). There still exists, particularly among elderly patients, to whom the inception of a National Health Service is still a 'new' concept, the view that services provided are a privilege, rather than a right. The writer has also experienced reluctance on the part of patients to criticise a service provided by individuals or a body of people who are generally liked and respected, and perceived to be working under difficult conditions. Paediatric nurses in particular are perceived by the majority of clients as being caring and dedicated people. Questions probing satisfaction must clearly distinguish between the service and the people who are providing it, while avoiding complete depersonalisation of the process. Finally, the 'relief factor' (Strachan, 1988) must be

considered when attempting to ascertain satisfaction with paediatric practice. When the child has safely recovered from surgery, is restored to his normal environment, parents may well be happy to report a retrospective rosiness when asked to comment on the quality of care received.

This study sets out to sample satisfaction indices in respondents who experience similar levels of use of the service, with the notable exception of the experimental group who receive additional care. The role of expectation in relation to subsequent satisfaction has been explored in a number of studies, mainly concerned with the adult client. Larson and Rootman (1976), demonstrated a relationship between expectation and satisfaction in the predicted direction, that is satisfaction was reportedly lower when expectations were not met. Parental expectations in relation to paediatric hospitalisation have not been explored apart from the overall measure in relation to preparation studies, which stem mainly from North America, where cultural and socio-political factors strongly influence expectation and subsequent satisfaction with care. However, Robinson, (1986) in her study of uptake of health care facilities found low levels of expectation among mothers of children about to undergo elective surgery. Strachan (1988) found a similar pattern in the pilot study, where expectation was either not considered by parents, or was entirely related to the successful outcome of the surgery. Parents on the whole did not expect to be considered when planning and carrying out nursing and medical care. This issue is discussed more fully in the present analysis which looks at the role expectations of parents. To the extent that client assessments of satisfaction with care are derived from expectation, those assessments are likely to change during the course of care provision, as the child progresses through his treatment and the parents and child acquire new knowledge which leads to reappraisal within the new environment.

A caveat must now be offered. As Locker et al, (1978) succinctly states studies of client satisfaction are not in themselves evaluations of the quality of care, either from the provider or from the recipient perspective. The data produced by satisfaction studies are therefore observations not evaluations and may be used as indicators of quality only if a clearly defined standard is available to effect a comparison. Paediatric standards of care have been discussed in recent years and a well defined framework exists which may serve as a guideline. However, personal experience over many years, alerts the writer to the danger of accepting such laudable initiatives as a *fait accompli*.

Standards are never fixed but must continually reflect changing patient needs and expectations, as well as changing paradigms on which the care is based. Mechanic (1978)

has highlighted the distinction between the ideal and practical in terms of client expectation of health care. This raises an important conceptual issue, in which the patients are satisfied because their expectations have been met, but the care received may have failed to meet all their needs, as defined by objective observers. This point is emphasised in the present pilot study, when parents expressed their satisfaction, but then went on to elaborate ways in which the service could have been improved. It also raises the point that parents hold expectations about different aspects of care. Stimson and Webb (1975) have referred to these as background interaction and action expectations. The interaction component appears more significant, in that studies frequently report the disappointment of patients in relation to the manner in which the service or care is provided rather than the nature of the care itself. This is also found to be the case in the present pilot study when parents frequently report feeling very satisfied (and go on to explain why they feel so) with the communication with nursing staff, while going on to express total dissatisfaction with the resources available to them while in hospital with their child. Locker, (1978) reminds us that if the client perspective is important, then the current research perspective would need to be widened if we are to gain more than assumptions from the study of satisfaction with health care provision. A logical development then would be to ask all recipients of the service to define their own priorities and evaluate the care they received accordingly, rather than have the criteria entirely provider defined.

This study looks at parental perceptions of the outcome of care received expressed as satisfaction with the care delivered, in order to compare satisfaction across the groups studied. In addition, satisfaction measures may serve to inform the providers of care about recurring issues which emerge in patients perception of the experience. If we are to respond to the changing paradigms of nursing and medical care as well as health care provision nationally, the profession must reconcile it's own priorities with those of the client in the formulation and implementation of policy.

5:8 Discussion of Measurement Techniques

Measurements indicative of disturbance or deterioration in children's emotional status are referred to in this study as emotional upset or psychological upset. Thompson (1986), reports considerable evidence in the literature that hospitalisation results in at least brief, transitory changes in children's behaviour, in their subjective assessments and possibly in physiological indicators frequently associated with upset, for example, pulse rate, sleeping habits, appetite, and so on. Data comparing hospitalised and non

hospitalised children, although extremely limited, indicates that hospital admission may alter the child's perception of pain and fear (Savendra and Tesler, 1981), produce fluctuations in psychometric indices, (Irwin and LLOYD-Still, 1974) and affect specific areas of their cognitive functioning (Reissland, 1983). Also, studies have shown that measures of psychological upset fluctuate in response to the treatment children receive, a finding that suggests that disturbance is common among children during the period of health care delivery. The effect of the absence of interventions designed to prepare or support the child during this time, for example, preparation initiatives, parental support and rooming -in, would be expected to be significant.

The present study aims to test the outcome of an individual approach to the preparation of the child and his parents. It is not the intention of the study to identify the efficacy of a particular aspect of the preparation employed. This approach, which has hitherto been untested, raises the concern for the possible confounding effect of interventions. The present study is based however, on the premise that it is indeed paradoxical to delineate individual aspects of preparation while addressing the uniquely individual nature of the process. Discussion of the pilot study will now be presented prior to turning to a discussion of the setting in which the main study took place.

5:9 Report of the Pilot Study.

A pilot study was conducted during the Spring of 1990. Data collection was completed within one month. The primary objective of this preliminary study was to test as many elements of the research proposal as possible, in order to rectify any problems prior to the main study.

The following aims were achieved:-

1. Instruments and scales were tested to determine if each measured what the researcher intended them to measure. Face and content validity was achieved for the instruments developed by the writer. The remaining instruments, soundly validated as a result of previous studies, were tested within the setting and found to be appropriate.
2. Testing to determine whether the procedures designed for operationalising the major variables, for example stress in children and stress/anxiety in parents, were feasible, valid and reliable. The constructs used, accurately reflected the observable behaviour of the child and the expressed level of anxiety of the parents. Similarly, the theoretical framework which underpins this study served to explicate and inform these observations.

3. Examination of the practical problems raised by data collection within a paediatric setting highlighted important areas to be addressed.

The Setting

A specialist "general" hospital, primarily designed to accommodate adult patients within a variety of specialist wards was selected for the pilot study. The Ear, Nose and Throat (ENT) unit, a 20 bed area serving adult patients within this speciality, reserve 10 beds designated for the care of children ages 3-14yrs requiring ENT surgical procedures.

The ward is staffed by Registered General Nurses (RGN) and Enrolled Nurses (EN) and is a training area for learners following the RGN course. The ward is also an area of experience for post-basic learners pursuing the professional studies module related to this speciality. Only one member of the nursing team also held the Registered Sick Childrens' Nurse (RSCN) qualification, during the course of the pilot work. The overall philosophy of the permanent nursing staff reflected the disparate nature of the age range of patients and their diverse needs. Although, in this mixed ward, resources do exist for children's play, these are available on mornings only, and organised by voluntary play leaders. Facilities for parents at the time of the pilot study were minimal. Parents were permitted, although not encouraged to stay overnight with their child. An easy chair at the cot side was the only sleeping facility available. No separate toilet or kitchen facilities were provided for parents, some of whom travelled from the Scottish Borders and intended staying for the duration of the childs' admission. On the whole, the nursing staff were able to circumvent the limitations and provide a calm and pleasant environment for child and parent. It is important to note however, that shortly after this study was conducted, facilities did improve, in that chair beds were provided for mothers who wished to stay. Staff canteen facilities were open to parents and the toilet areas were extended to provide showers. Fathers however were strongly discouraged from staying over night, indeed were asked to avoid visiting the ward at specific times, since the female adult patients were in need of privacy. Clearly, the ward remains an area more tailored to the needs of the female adult patient, rather than those of the child and his family.

The reality of preparation for paediatric hospitalisation within the area of the pilot study, is that the nurses are unable, within the present system and stated goals, to provide an individualised approach to preparation. Necessary allocation of resources is used to justify post-hoc the attention to preparation that is given.

Twenty children and their parents were selected at random from the waiting list (testing

the table of random numbers to be used in the main study). All parents and children who were approached consented to take part in the pilot study. However, three of the initial sample were found to be unfit for surgery and were sent home without treatment. The pilot sample therefore totalled 17 children and their parents.

Methodological Changes as a Result of the Pilot Study

Five of the six data collection tools were tested in the pilot study. The pre-admission diary, intended to serve as a second control, was not tested since this instrument is of value as an 'attention control' therefore is of use only when the experimental treatment is initiated.

The practical problems raised by the temporal issues of data collection were apparent. Since the present study intended to use a total of six research instruments, timing in relation to admission, parent convenience and methodological rigour required some modification. Parents reported that, although they were happy to participate in the study, they found they were unable to concentrate on requests for information about their child *at the same time* as the information about admission was received. Although administratively less convenient, changes were planned for the main study and a time interval between receipt of hospital and research information incorporated.

Ten mothers completed the request for pre-admission information. Most expressed their interest and welcomed the opportunity to write about their child. As one mother put it, "It gave you something to do, something practical, it stopped you fretting and worrying about things"

Face and content validity of the pre-admission questionnaire was apparent, as was the subsequent post-hospital questionnaire and enabled baseline comparisons to be made.

Some key issues about the conduct of research within a paediatric clinical setting were also raised during the course of the pilot work. Standardising conditions of the research interviews was an important consideration. Attention also required to be paid to the initial responses of the child on admission to hospital and the need to allow sufficient flexibility in the time and nature of the initial adjustments. For example many children were fascinated by the fish tank in the playroom area and were happy to leave parents and spend time with other children. Conversely, other children felt more threatened by the immediate environment and required the undivided attention of parents who were observed to utilise considerable emotional resources in attempts to reassure their child. Securing standard interview conditions therefore, involved the caveat of introducing flexibility and creativity in approaching the individual family and assessing their

present adjustment.

The practical points relating to data collection within a clinical area and particularly within a childrens' unit were apparent. Difficulties were mainly due to the lack of a quiet area in which to talk to parents while their child could either be with them, or be clearly seen by them. Co-ordination of interviews posed minor difficulties, in that it was important that the sequence of interviews remained consistent and that all families were seen by the researcher before any specific medical treatments were carried out. Satisfactory standardisation was possible with co-operation from the admitting nurse and doctor, who were able to set up a smooth sequence which accommodated individual need, for example, mother having to leave early to see to another sibling .

Minor changes were required to the pre-admission questionnaires and the parent response instrument to remove ambiguity and perceived repetition in some questions. However, it remained necessary to include some common ground between the pre-admission questions and the admission schedule, to take account of possible attrition rates if parents did not bring the former instrument with them on the day of admission to the ward. Consideration was given to asking the parents to mail this back to the researcher, however, it seemed important to retain personal contact and to emphasise the relevance of the questionnaire in relation to the child's admission.

High levels of pre-admission anxiety among mothers in the sample were apparent from the responses made both on the GHQ and also on interview schedules. This confirmed the content and construct validity as applied to the present study and previously soundly validated within other settings. Fathers, on the whole perceived their role as one of support and 'holding the fort' at home to enable the mother to be with the hospitalised child. When father was also present during the admission interview his role was largely one of confirming the mother's responses. Although there were two amusing incidents when mother was describing the child's routine behaviour and father added his own perspective, their comments were illuminating rather than contradictory. This point was taken seriously and emphasis was laid on the same respondent completing all requests for information which effectively meant that all mothers were the respondents.

Given that it was specifically not the intention to attempt analysis of this small preliminary study, the outcome measures were studied in relation to the setting and preparation given to each family. Responses on post-hospital questionnaire revealed a high level of upset and continued physical and emotional problems in fifteen of the seventeen children sampled. The disturbances were related mainly to separation anxiety, for example, following mum around the house, reluctant to go to school and sleeping in parents bed. In addition ten children experienced eating and sleep problems, that is;

having to be persuaded to eat, difficult to settle at night, and demonstrating regressive behaviours in relation to autonomy and social behaviour. Also six children were reported to be physically still 'peaky' or 'not himself' at two weeks post transfer home.

Parents perceptions of satisfaction with care and with preparation was expressed by all mothers in the sample. Indeed many parents used the post-questionnaire as a constructive tool for their opinions and suggestions in light of their recent experiences. A wealth of key issues of considerable nursing, medical and managerial import were highlighted by parental responses. The limitations of the 'system' in providing adequate resources for parents of children in hospital was a recurring theme. Parents seemed able to compartmentalise their experience in terms of health service provision, and issues relating directly to nursing care. Satisfaction with the standard of care received was interpreted as being 'very satisfied to very dissatisfied' with comments to support these choices in the majority of responses. Constructive comments in relation to the conduct of nursing practice were made. These focused largely on the need for flexibility when caring for the child within an adult setting.

Inter observer reliability

A crucial part of the objective assessment of the child's manifest upset and co-operation during maximum stress points (as defined in the discussion of this instrument) is carried out by the admitting senior medical officer, the nurse assigned to the care of the child during his admission and subsequent care, and finally, the anaesthetist. While this manifest upset and co-operation scale was soundly validated during previous empirical studies, some important areas required to be addressed before sufficient rigour was secured in the reliability of the observations made.

i) The Medical observer. Assessment of the child's reaction to non-invasive medical examination on admission, in the presence of parent/s involves no physical pain or discomfort, but does require a degree of co-operation. Inter observer reliability was secured without difficulty, since the parameters of upset and co-operation were easily identified in this situation. No criteria were laid down in relation to how the child was enabled to stay calm and co-operative, for example, whether he required to be held and comforted by mother. The variable under investigation was the presence or absence of upset and co-operative behaviours.

ii) The Nurses as observers. It was clearly essential to enlist the support and interest of the nursing staff in the recording of manifest upset and co-operation, while remaining cognisant of the restrictions placed on the researcher when asking nursing staff to invest time in research initiatives. The pilot study addressed this issue by monitoring carefully the time and administrative efforts made by the nurses involved. Indeed this was a prerequisite to the main study, since additional demands on clinical staff who are already overstretched within existing resources, would have been unacceptable. In the event, recordings were based largely on observations which the nursing staff would routinely make, the only addition being the need to be more explicit in their description.

Inter-observer reliability of nursing observations posed more difficulties and highlighted some important areas to consider prior to the main study. In essence, the fact that the nursing staff on the unit had not undergone training leading to the RSCN qualification indicated that the staff were looking at different criteria to measure the same phenomenon. The most striking example of the dichotomy between nurse and researcher ratings, is the observation of the responses of a five-year old boy in the sample. This child's parents had some distance to travel and were not with their son as much as some other parents who lived more locally. This child was assessed as calm and settled by the nurse observer. He was considered by the researcher to be apathetic and quietly distressed. Clearly, an awareness of the level of knowledge of principles of growth and development is inadequate when assessing the nurses' ability to accurately assess the child's emotional state. Reference requires to be made also, to the ability of the nurse to apply these principles in her care and observation of the child of varying cognitive and emotional stages of development, who finds himself coping with a variety of environmental challenges or threats.

This issue raised questions about the most effective way of predicting more precisely, the knowledge base of the nursing staff who would be responsible for blind observer ratings of children's manifest upset and co-operation in the main study. (This was achieved during discussions with the staff involved and a detailed knowledge of the content of the teaching curriculum followed by the two Staff Nurses, known by the researcher as a result of her years experience of teaching on the RSCN courses.)

iii) The Anaesthetist. Again a most important issue required to be reviewed. The Consultant Anaesthetist in charge of paediatrics (but who also was mainly responsible for adult anaesthetic care), adopted the view that children who are not calm and co-operative should not in fact be considered suitable candidates for a general anaesthetic. This stance therefore seemingly invalidates the observation of the child's response to

induction as recorded on the upset and co-operation scales. In the event, the writer gained access to the operating theatre and observed the anaesthetist as he prepared the child for induction. The children were, without exception, reassured and rendered calm and co-operative by the anaesthetist who displayed considerable expertise in calming the troubled child. The attitude of this doctor was therefore coloured by his own expectations of self and the knowledge that he could be successful in his aim of securing a calm and relaxed child prior to induction. When asked what he expected of the nursing staff in preparing the child for theatre, this consultant replied:

"...I expect the nurses to do their best with the children, but what can they realistically do when you get parents who don't even tell their child where they are going on the day of admission to hospital".

(Consultant Anaesthetist, pilot study).

The consultant later confided that a five year old boy suffered a cardiac arrest during induction. In the consultant's view this was due entirely to the extreme state of distress the child was in when he arrived for surgery. The parents were also visibly upset and could offer their son no reassuring support. The child fully recovered and was sent home without surgery. His parents received counselling.

Discussions with the two Consultant Anaesthetists who would be involved in the main study then took place. Their expectations were elicited as were their attitudes to preparation. The views expressed are recorded as follows: (recorded as fieldnotes, May, 1990)

"A child does not go through all the upset of admission, pre-medication, separation from parents and all the rest, just to be sent home without surgery because he is understandably afraid and showing it when he arrives in the theatre. We hope the parents and the nursing staff have played their part. We do our best to reassure the child and then get on with the job."

Senior Consultant (a)

"It helps to meet the children the night before, although clearly for medical reasons, we like to spend a little time talking to the child and parents if there. I wonder if they remember that they have met us though, perhaps the familiarity of the voice is reassuring. If the nurses have done their job well, the child should not be too distressed. They vary of course, and we have to remember how very frightening the operating room is to a small child lying on a trolley, feeling drowsy with a sense, no doubt of unreality. All children in this unit have been taken to the theatre 'en masse' by the nurses, so the environment is not completely unfamiliar to them. When the child is very distressed, yes, then we worry, safe anaesthesia is our goal, that also means a calm and co-operative child".

Consultant (b)

Preparation for Hospitalisation

Children in the pilot sample were prepared under conditions similar to those planned for the first control group in the main study. That is, information giving is the central theme and is conveyed by way of leaflets describing the practical details of arrangements prior to the child being admitted, this is posted to families up to two weeks before surgery. Invitation to telephone the ward and discuss aspects of the impending admission with Sister or Staff Nurse, or to arrange a pre-admission visit is contained within the leaflet.

Post Hospital Responses.

While careful attention was paid to the need to enlist the full co-operation of respondents during the interviews, the reality of parents returning home with a child who still required much attention and care from a mother who was exhausted and whose resources, both coping and physical were expected to be reduced, required further personal contact. The researcher therefore, by prior agreement, sent an informal post card to each family before sending the post hospital behaviour questionnaire. The questionnaires were then mailed out to arrive two weeks after transfer home.

This approach appeared to be very successful, as fifteen of the final seventeen families returned their questionnaires without further contact. The remaining two respondents were contacted by telephone and asked if they would like a repeat form. Both agreed, one family stating that they had not received the questionnaire and the other that the toddler had drawn on it. Both questionnaires were returned within a few days of the second mailing.

Further attention to coding and layout of the PHBQ was required following discussion with a statistician who had also advised on the preliminary selection of questions for some instruments.

A fieldwork diary, started by the researcher with the aim of keeping a careful check on the sequence of questionnaires sent and the responses returned, required minor adjustment in layout, but proved an essential item in the pilot and subsequently in the main study.

Feedback to Ward Staff.

While clearly, this preliminary study was not intended to test any intervention or to make any kind of statement about preparation for hospitalisation, the ward staff were very interested in receiving some feedback. The responses of parents proved an important area to share, since issues of satisfaction with care received and suggestions as to how the

experience could have been a more positive one for child and parents, were given freely . Much scope for improvement in facilities exists within the area used for the pilot work. The most sensitive issues of staff attitudes towards change and towards caring for children within an adult specialty were addressed rather more obliquely. Reference was made to the situation and approach used within a Sick Children's Hospital, comparison of resources including trained staff was thereby discussed at some length. This proved a most worthwhile meeting, the staff were keen to look at alternative approaches and to address the comments, especially the practical ones in relation to lack of facilities for parents, recorded by parents.

The Nursing staff requested copies of the final report of the main study, this is viewed as an important opportunity to foster the link made during the pilot work and share the outcome with staff working in less than ideal circumstances, but with a willingness to be open to change.

In summary, the aims of the pilot study were achieved. Further important issues also emerged, as described above. In essence, time for reflection, analysis and synthesis of the theoretical and practical issues raised by the pilot work was necessary prior to final planning of the main study.

A key component of the substantive study is the planning and development of the experimental intervention. It is to a discussion of how the approach to preparation tested in this study evolved and was subsequently refined and tested, that we now turn.

CHAPTER 6

PREPARATION FOR PAEDIATRIC HOSPITALISATION.

6:1 The philosophy of the Experimental Intervention.

In planning and developing the experimental intervention, an extensive review of the literature was undertaken (Chapters 2-4). In particular, attention to the limitations of past intervention measures was a key point in the planning and development of the preparation approaches devised for this study. Previous reviews (for example, Thompson, 1986), attest to the failure of programmes to relate to the individual needs of the child. This is particularly evident in preparation strategies which include children within a wide age range and administer the *same preparation technique to all* (for example, Wolfer and Visintainer, 1979, Peterson, 1989). The present study attempts to circumvent this difficulty by applying a discriminating approach to preparation in which the individual needs of the child and his parent will be known. In addition, the writer is aware of the need for intervention approaches to be implemented by the nursing staff within the clinical area of the study. Previous studies have depended on the researcher implementing the intervention for the purpose of the study, then withdrawing from the clinical area when data collection is complete (Ferguson, 1979; Elkins and Roberts, 1984). The present study considers the exclusive involvement of the researcher a limitation and therefore plans to involve the nursing staff at the earliest stages and throughout the experimental intervention. In this way it is expected that the staff will have the expertise and motivation as well as the empirical evidence to continue with the preparation approach at the conclusion of the study *if the research evidence upholds the value of the method of preparation tested.*

In developing the approach to preparation described in this chapter, the writer drew upon past personal clinical and teaching experience, as well as the important contribution from nursing colleagues who are experts within the specialist area studied.

A review of the coping mechanisms employed by children was made prior to the development of intervention strategies designed to assess coping within the treatment conditions, since the theoretical relevance of an intervention is closely related to the nature of the particular stressor around which the intervention is oriented. The stress and coping paradigm of Lazarus, which underpins this study, therefore informed the

intervention strategies adopted. Attention also focused on the developmental framework which informs paediatric research, as much as on the critical analysis of existing preparation themes.

The experimental intervention therefore was informed by a critique of past empirical studies, as well as by the experience of the researcher and clinical colleagues. In this way, realistic appraisal of resources available were made at the outset of the planning stages. Previous studies have been criticised for applying 'overly creative, expensive and time consuming interventions' (Thompson, 1986). For example puppet therapy (Cassell, 1969) and stress immunisation techniques (Peterson and Shigetomi, 1982). No training was given to the ward staff in the use of these approaches, and the interventions were not carried on after the period of data collection.

The criterion of 'success' of the intervention will be assessed in terms of outcome measures of child and parent responses. In addition, formative evaluation of staff perceptions will form an integral part of the assessment. Five research instruments will inform the outcome of the experimental intervention, that is, before, during and following paediatric hospitalisation and surgery. The quantitative analysis will present statistical outcome measures while the qualitative analysis will explore the personal meaning of the events which will include a direct assessment by the parent, of the perceived efficacy of preparation.

The ultimate goal in research in both health care and illness related stressors is ascertaining how to enhance patients' ability to cope effectively with the stress they are experiencing. Aeurbach (1989) contends that this research generally has been insufficiently theoretically grounded. The main thrust of Aeurbach's critique is that the stimulus complex confronting the individual has rarely been conceptualised in terms of the nature of the coping demands it poses for that individual and further, that intervention strategies have often not been formulated to meet those demands. While accepting the principles explicated in the above critique, the writer is aware of the need to address the specific nature of paediatric research and to directly ask "coping with what?"

The present study enlists the cognitive appraisal model of stress and coping (Lazarus, 1984) in order to address the above criticisms and answer the research questions as they relate to children in hospital.

As has been reviewed in the literature, few structured programmes exist at present in the majority of paediatric hospitals and in general hospitals with paediatric wards/beds. Some important progress has however been made, particularly in relation to the identification of the need to involve parents more actively in the care of their hospitalised child (Care by Parent's Schemes, Cardiff, 1990).

The burden of proof for both the necessity and the effectiveness and cost effectiveness of a new approach rests with existing practitioners and researchers. Given the hierarchy of concern within children's hospitals which now ideologically if not always in reality, places the emotional well-being of the child as an established priority. Preparation approaches which are known to be effective and which are implementable are likely to be favourably reviewed by the professionals involved. The intervention strategies formulated to meet the demands required consideration of the following specific areas:-

6:2 Development of the Experimental Intervention.

Key Areas Addressed When Developing the Experimental Intervention.

1. Children in hospital are separated, at least for a part of the time, from their families and to a greater extent from the familiarity of their day to day activities and relationships. These relationships normally provide dependability, predictability and protection.
2. Children who are admitted to hospital are presented with the challenge or threat of having to adjust to unfamiliar routines. These routines are determined and supervised by caring, attentive professionals who are nonetheless, strangers.
3. Children in hospital experience varying degrees of restrictions on their behaviour and activities. They are largely expected to integrate into the needs of the ward routine with the attendant implications for self-care and autonomy. Preparation for the "patient role" is rarely addressed during preparation initiatives. (Beuf,1979)
4. Children in hospital experience the same developmental needs as non-hospitalised children, however, the wide variability of cognitive ability, which is too frequently linked synonymously with chronological age, often obscures the child's actual needs. In addition, children's responses to stressful encounters often precipitate some (largely) temporary regressive behaviours.
5. Children are vulnerable to misunderstanding, particularly of the purpose and effect of treatments and invasive procedures, which are an integral part of illness and surgery. The literature review supports the need to address the diversity of children's conceptions of illness and medical treatments.

6. Children admitted to hospital require a degree of autonomy to encourage continuity of self esteem if perceived control over the events is to be maximised.

The experimental treatment was therefore based on the need to test an approach to preparation for paediatric hospitalisation which addressed the needs of the individual child and his or her parents. In effect, the need to explore the personal meaning of the event for each child is implicit in an acceptance of the stress and coping paradigm which informs this study. Clearly this required knowledge of the predictable cognitive and emotional development of children within the developmental range studied. This knowledge then required to be applied to the actual needs of the child and parents, as assessed by experienced Registered Sick Children's Nurses and expressed by child and parents during the experimental intervention. Much has been said about hospitalisation as a constructive learning experience for children, however, as explored during the course of the literature review, the overly 'sentimental' appraisal of the hospital setting may exaggerate the potential benefits .

Current preparation approaches, where indeed they do exist, are planned on the basis of cost containment, rather than on sound child development or preparation research findings (Peterson,1989). The present intervention is based on the need to be more discriminating, to address child, family and situation variables, in an effort to relate preparation to the individual child and his parents.

An explicit aim of the experimental intervention is to present an individual approach relevant to the needs of children and their parents based on identification of the demographic, interpersonal and environmental variables which invariably exist, while addressing the limitations of resources available to the professionals engaged in any subsequent preparation strategies. An approach which is capable of being implemented within existing resources by the staff normally responsible for child and family care, is therefore a key pre-requisite to this study.

The following principles are applied:-

1. The opportunity to identify the child's perceptions and health care beliefs relating to the impending admission is given, time being set aside for the Nurse responsible to relate to each family as they progressed through the preparation. Parents level of understanding of the events is also assessed, as are the likely effects of parental preparation before and continuing after the visit.

2. Children's recent health care experiences are known, that is, the sample included children who have not been hospitalised within the preceding year prior to admission. However, child responses to health care settings, for example, how the child coped with the outpatient consultation and to routine visits to the family doctor and dentist are discussed with the parents.

3. Sufficient time is allowed for preparation. Children vary widely in their readiness to assimilate new experiences, they need to interrupt and to react to what they are seeing; they may require clarification and reassurance. Younger children in particular require time, repetition and support, from parent and professionals, to integrate new provocative, threatening or challenging information if the risk of misconceptions are to be minimised. It is important, albeit very difficult to determine in young children, worries, preoccupations, misinterpretations and misperceptions of information which will influence their subsequent adjustment to the hospital experience, and ultimately, the effects short and longer term, of that experience. A group tour is therefore considered inappropriate to meet the above criteria.

4. Multisensory experiences are presented with the opportunity to interpret their meaning at an individual level. For example, the sights, smells and sounds of the ward environment can pose a threat to some children while to others they represent a fascinating adventure. Children are given a quiet time to assimilate these experiences. Medical equipment which can be safely touched is made available to use as therapeutic play. This is kept to a minimum and represents only that which the child will encounter during the course of his treatments. An experienced play leader as well as a RSCN. is on hand to respond to children's use of the equipment, in particular to emphasise the difference between fantasy and reality.

5. The opportunity to establish a relationship with the staff, which could form the basis of a trusting relationship during the child's in-patient experiences was considered an essential component of a preparation approach. For this reason the same staff were also on duty during the child's admission procedures and subsequent care, although clearly were not involved in observer ratings of manifest upset and co-operation, which were conducted 'blind'.

6. Child and parent initiated preparation is encouraged. An implicit goal of this approach to preparation is to maximise the opportunity for the child to gain some control

over the events and to identify that which may prevent parents from assuming the level of competence they would normally expect of themselves in caring for their child.

7. Readiness to listen, observe and respond to children and parents verbal and behavioural reactions to health care information. A time of reflective interaction, which presents the potential for reappraisal of perceptions related to the new experience, is possible within this approach, given that appropriate support is at hand. It is recognised as important to attend to not only what is said to children and their parents, but also to what children and parents perceive as having been said.

8. Reassurance is an important element of the initial contact with the child. In this context reassurance is based on the confirmation by the nurse of practices that *will* be possible, aimed at reducing the child's level of uncertainty and degree of unfamiliarity of the setting. An example is encouraging the child to bring to the hospital, objects which are important to the child, for example a favourite old blanket, teddy, or doll. These possessions, serve as important transitional objects in the separation-individuation process (Ainsworth, 1982) and are therefore important within a developmental approach to preparation.

Parental Preparation.

Although an integral part of the whole, the important additional factor being addressed is that parental counselling is provided within the experimental treatment condition. Parents are at liberty to use the time set aside to meet their individual needs in privacy and with expert resources at their disposal. In this way it is expected that the parents may be encouraged to express their anxieties and expectations and be actively supported in their choice of treatment for the child.

Preparation of the Staff for implementation of the above role.

Following discussion with the Director of Nursing Services and with the senior Nursing staff on the ward, three experienced Registered Sick Children's Nurses, who had wide experience of the specialty as well as post registration experience of relating to parents and children admitted for surgical treatments, were invited to be responsible for the preparation of the experimental group. The staff involved had also undertaken a professional studies (2) module, which included theories and practice of counselling in relation to their role as staff nurses within a sick children's hospital.

Discussions then took place with the researcher and participating staff nurses and a preparation strategy was adopted. The principal aims being negotiated with the staff involved, that is; to familiarize child and parent with the ward environment at their individual pace and not as part of a larger tour. To orient the child and his parents to the hospital milieu in general, and in particular to locate the areas from which the child and parent would enter and leave the hospital in relation to the ward. To reassure parents of the flexibility of the nursing care plans which may readily accommodate parental involvement in the child's care to the level decided by the parents and based on their other family commitments, as well as the needs of the child in hospital. Also a clear statement of the specific nature of the preparation was negotiated with the staff prior to planning the strategy; that is the nature and conduct of the preparation in relation to staff, environment, activities and addressing the role of the child as well as that of the parents. Reflective interaction was an important element of the intervention. Time being given to allow children to come to assimilate and come to terms with the information received. The potential for reappraisal of perceptions related to hospital and health care treatments exists within such a preparation strategy, given the presence of appropriate family and professional support.

The specific detail of the intervention is as follows:-

It is important to reiterate that the child and parents were prepared at an individual level, therefore the following strategies were adopted to meet these individual needs. The experimental intervention took place at the same time each week, planned for a convenient time after the normal school day, at a time when the ward was calm and unhurried. No theatre lists were undertaken on that day. Siblings were invited to use the playcentre facilities adjacent to the hospital (escort provided) to enable the mother to devote her attention to the child being prepared for hospital. The in-patients were children who were at similar stages of recovery from ear, nose and throat operations. The numbers attending each preparation afternoon were kept small for the purpose of affording each family the required individual attention. Given that the average admissions to the ward on each receiving day numbered ten to twelve and respondents from both admission days each week were included in the sample, then up to twenty four families were admitted. One third of this group were assigned to the experimental condition and therefore a maximum of eight families attended the preparation sessions. The times of preparation were staggered to facilitate the calm, unhurried atmosphere, which was considered to be essential to the success of the preparation.

The family was met by one of the staff nurses and welcomed to the ward. An informal chat took place aimed at setting the group at ease, this was not related specifically to preparation, and involved encouraging the child to relate to the staff nurse who in turn got to know something of the child and his present attitudes. A tour of the ward area then took place, the central focus being the playroom where a playleader was on duty to welcome the children and show them the facilities available. In addition to toys, books and games appropriate to the 3-7 age range, medical instruments were laid out and the child was left to select his own activity. The playleader and staff nurse were on hand to guide their use. Colouring in activities were available, these were related to the specific nature of the treatments to be done. Afternoon tea was then served and the parents given the opportunity to meet with the other families likely to be in the ward at the same time. Following this informal gathering the child and his parents were then asked if they would like to spend some time alone with the staff nurse. Parents could use this time to clarify their own impressions and talk to their child about what he had seen. Counselling took place within this time and children were encouraged to explore the play facilities and meet the other children, or alternatively, to remain with the mother if this was preferred.

A short sequence from a video-tape recording which depicts a five-year old girl being admitted to hospital for ear, nose and throat procedures was then viewed (Children in Hospital, 1989). The children were then invited to go round the ward again with or without their parents and ask any questions they wish. Large group tours and question and answer sessions were avoided since they do not provide an atmosphere conducive to meeting individual needs. Simple aspects of preparation, for example, showing the child the bracelet he/she would wear when admitted and providing one for his special teddy or doll. Showing him the bed/cot which would have his name on it and showing the child how easy it is for parents to find him, all addressed the principles of preparation outlined above.

Involving the parent as much in the preparation as possible, addressed the reality that parents knowledge of their own child and his reactions to stressful situation, supersedes that of the professionals in the majority of cases. Parental ability and readiness to prepare clearly vary widely. Time was spent discussing with parents what they could actually be *doing* while their child was receiving in-hospital care. In particular, post-operative management was reviewed and the parents role in this aspect of continuing care was discussed.

All children were given a badge depicting the ward mascot and a colouring in activity related to continuing preparation which they were asked to colour in and bring back on the

day of admission. The posters would then be placed above the child's bed until transfer home when he/she would be invited to take it away. Parents were reassured that they could telephone the ward at any time in the intervening few days prior to their child's admission, should they have any further issues of concern.

6:3 Control Conditions

Control group 1.

Control groups are of practical utility in that they provide baseline outcome data that enable evaluation of the extent to which interventions produce effects superior to that which may be expected from standard hospital care. (Outcome measures are defined in a preceding section)

The first control group received standard hospital preparation, which is given to every child admitted to the Sick Children's Hospital ("Routine hospital conditions"). The only addition was some specific information relating to the nature of the surgical/medical treatment to be performed. This routine preparation involves mailed information sent out to reach the parents 2-3 weeks prior to the child's expected admission. It contains practical information on how to get to the hospital from a variety of locations in and around the city. Visiting arrangements are detailed, as are a list of necessary articles to be brought with the child. Parents are advised that they may remain with their child, but that rooming -in facilities are generally reserved for parents of ill children, or for parents who have travelled and have visiting difficulties. Parents are reminded that they may receive help with travel and sibling care during the child's hospitalisation. Implicit within this information is the acceptance by health care professionals that the parents have the right and largely, the expectation of being involved to varying degrees in their child's care. Some mention is also made of the opportunity to arrange a visit to the ward prior to admission date, the onus for this preparation is however, firmly left with the parents to "ring the ward and arrange with the Sister or staff nurse..."

Control group 2

The purpose of assigning a second control group is to serve the function of ensuring that outcome differences result from the specific intervention components being manipulated, rather than from non-specific effects of the interpersonal encounter. Clearly a caveat has to be offered in that families assigned to control (2) conditions should engage in what is intended as neutral interaction, that is "therapeutically inert from the standpoint of the

theory of the therapy being studied" (Rosenthal and Frank, 1963, p279).

In essence, the families in control group (2), received a diary, mailed out 10 days before expected admission. Parents were asked to record on a day to day basis, aspects of their child's routine activities and general behaviour during the seven days prior to admission. Parents were then asked to bring the diary to the ward with them on the day of admission, when the researcher would engage in informal discussions with each of the families about the recorded content of the diary. The focus was not related to preparation, but on an overview of the child's normal activities. (see Appendix 1) The diaries were then retained by the researcher and not looked at until data analysis was complete. The researcher is aware that there may be an element within such encounters of stimulating emotion focused coping in the parents. In order to create credibility and command attention in parents in states of heightened anxiety, a fair degree of rapport is required. However this criticism must be balanced against the implicit value of attempts to distinguish between the effects of the experimental treatment and the effects of attention.

It is to a description of the setting in which the main study was conducted that we now turn.

CHAPTER 7

THE MAIN STUDY - Data Collection within a Paediatric Clinical Area.

7:1 Description of the Setting in which the study took place

The Hospital Milieu

The study was conducted within the Regional Sick Children's Hospital, a general and specialist centre which cares for children from birth to twelve years of age. Older children may also attend as in-patients and out-patients, particularly if they have been receiving specialist care within the centre during earlier childhood. The hospital is child oriented with many years of expertise reflected in the many departments which make up the network of facilities available to care for the sick child and his family. Living-in facilities are available to the families of sick children and to families who live some distance away.

The hospital serves a wide geographical catchment, with children from the northeast of Scotland and outer isles as well as children from the Scottish borders and from local urban and rural areas being referred for specialist care. The infrastructure is designed to meet the needs of the hospitalised child, the decor as well as the underlying philosophy reflects the concern for the well being of the sick child and his family. The hospital enjoys a reputation as a centre of excellence in relation to the medical, nursing and support care it provides. The College of Nursing, which currently prepares learners who already hold a general nursing certificate, (RGN) for registration on the Sick Children's Register (RSCN) currently situated in the vicinity of the hospital. At the time of the study, the wards are staffed by qualified sick children's nurses and by learners who already have a nursing qualification (RGN), following the shortened RSCN course. All wards have at least one sister or charge nurse who is responsible for the quality and standards of nursing practice. On occasions, agency nurses who are not necessarily RSCN. will be asked to step in when staffing levels are inadequate. The nurse manager responsible for each group of wards/departments, is in turn responsible for the deployment of appropriately qualified and experienced staff to each ward area.

The hospital enjoys the facilities of a playcentre which provides supervised play and care for the siblings of children in hospital, the purpose being to enable parents to spend time with the sick child, free from anxiety about the care of other children. As in other children's hospitals, the social work department has a high profile. Assistance is given to any family who requires help with visiting and other social issues connected with the admission of their child. The hospital Chaplain is a regular visitor to the wards and departments and practices at an interdenominational level, families are also encouraged to contact their own minister if they wish. Play is an integral part of the care within the hospital. Registered play-leaders are employed and provide a service to children confined to bed, as well as to the ambulant child who has access to the bright, well stocked playroom. In the absence of the playleader, for example, at weekends and during the evening, the nursing staff are familiar with the play needs of the hospitalised child and are well able to meet them on an individual basis. Parents are encouraged to continue involvement in the child's care, this relates to play activities, similar to those enjoyed at home. Favourite dolls, teddies, books and games may be brought into hospital with the child.

7:2 The Specialist area in which the study was conducted.

Facilitative and Restrictive Practices.

The ear, nose and throat unit is a 25 bedded area caring for children with a range of ENT problems. These are generally of a non-acute nature, and most admissions are elective, allowing opportunity for preparation and some flexibility of the timing of admission. Emergency admissions when they do arise are generally for the removal of foreign bodies lodged in children's ear nose or throat, the treatment of acute nose bleeds or re-admissions due to secondary haemorrhage following adenotonsillectomy. From time to time neonates may be admitted to the ward suffering from congenital problems. The unit is staffed by one ward sister and a minimum of five staff nurses supported by up to eight student nurses.

The general atmosphere of the unit is one of calm efficiency. The ward is brightly decorated, each child has his own bed/cot, and locker and his name is colourfully printed on his bed. The child then identifies 'his space' and is encouraged to arrange things in his locker and to explore his new environment. The design of the ward facilitates easy observation of all children, being a traditional 'Nightingale' type. The playroom is situated at the end of the ward. Play being supervised, either by a playleader, a nurse or by the parent. That hospital 'cannot be home' is axiomatic, and many writers contend that with insightful planning, negative aspects may be minimised and the experience of being

in hospital rendered a constructive one for at least a proportion of the children. (for example, Prugh,1983)

Facilities for parents are the same as those in the hospital generally. Rooming - in facilities are available, but since the accommodation is limited to some 20 bedrooms, when demand is high, only parents of seriously ill children or those parents who are unable to travel between home and hospital are able to secure a room. The cafeteria is open to all resident parents; others have access to another canteen run by the WRVS which is open between 10am and 4pm on weekdays. There is a parents sitting room where families can have a quiet time and smoke if they wish. At present there is no 'non-smoking' sitting room available to parents. Admissions take place on three scheduled days each week. The numbers of children admitted varies between 4 and 14, depending on the availability of the consultant, and on the number of cancellations made at the last minute. It is the ward policy to arrange last minute admissions, by contacting parents by telephone and offering a bed to ensure maximum use of available list space. Clearly this policy offers no time for preparation or adjustment and no children within this category were included in the study.

The operations are conducted by senior consultant paediatric ENT surgeons, and the anaesthetic care is delivered by an experienced consultant. Children are first admitted when the children already in the ward are well on the way to recovery, The ward therefore conveys an atmosphere which is calm, unhurried and relaxed.

Children are welcomed to the ward by the nurse who completes all the necessary admission and pre-operative procedures with the child and his parents. This procedure is conducted in an unhurried and relaxed manner and children are encouraged to integrate with other new children and to explore the playroom and meet the playleader. The emphasis is clearly on attempts to reduce the anxiety experienced by parents and the fear and apprehension often expressed by the child during his initial contact with the hospital milieu. Prugh (1983) estimates that children in hospital have contact with some twenty six people during any twenty four hour period. The most basic challenge would appear to be co-ordinating the conduct of the various activities to facilitate a calm and unhurried environment. The activities within the specialist unit studied were planned to ensure that the child has contact with as few professionals as possible during the period of hospital care.

Visiting Arrangements follow the pattern practised by the hospital generally and incorporates the recommendations of the Platt report (1959) and subsequent NAWCH reviews. That is; free and open visiting by parents is encouraged. The admitting nurse

specifically asks each family if they have, or envisage any difficulties which may prevent regular contact with the child throughout his stay in hospital. There is however a paradox. Parents are asked to leave the ward on the morning of operation up to one hour before the child is taken to theatre, and requested not to return until the operation list has been completed. This is usually up to three hours. The following extract from a NAWCH report, highlights the contradiction of the above ward policy,

It is very important that parents are allowed free and unrestricted access to their child, particularly during times when he is likely to be upset and anxious. ... Regular visits will make your child feel more secure during his stay.

(NAWCH booklet, no. 28)

As will be seen during the discussions of the analysis, this issue is a highly contentious one and one which causes considerable anguish to parents and distress to the child. The rationale offered by the staff for this practice is simply that the physical resources of the area are limited, that is, there is no anaesthetic room, therefore, all children are taken to a room close to the operating theatre where they are 'entertained' prior to being carried onto the operating table . The staff are of the view that the presence of parents would greatly complicate the smooth transition of children from waiting area to theatre. The author has had some experience as a ward sister in charge of the same area, albeit some years ago. The presence of mothers had variable effects on the child and on the efficiency with which the lists were conducted, however, it is in this writers view, a questionable practice to deny the parents access to their child at such a time, and may be seen as professionally unacceptable and developmentally harmful. The conflict arises when nurses then have to spend some time consoling distressed mothers who 'break down' as they see their child being carried into theatre. The effect of mother's distress on the child must also be addressed. This issue will be discussed further in a later chapter.

Parental involvement in the child's care is encouraged. The philosophy adopted by the staff addresses the dilemma which parents often find themselves in when one of their children is in hospital. That is; the staff are aware of the difficulties mothers have when trying to care for children at home and in hospital. Attempts to meet the individual needs of child and parent while, at the same time being aware that the parent may have to leave the ward to attend to other children at home is the approach adopted by the staff. As will be addressed during subsequent discussions this emerges as an important area and raises issues relating to parental confidence in their own competence. Some parents may

show strong 'rivalry' with the nurses and doctors, interpreting professional competence in caring for the child as a reflection on their ability as an effective parent.

The rapid turnover requires that the ward functions as a highly organised area. However, attempts to build in some degree of flexibility are made. For example, although siblings are not encouraged to spend full days in the ward, they are permitted to stay if no other acceptable option is open for mothers. Mothers with babies who are still being breast fed, or who require other care from the mother, stay in the ward with the hospitalised child. Relatives other than parents are not permitted to visit on operating days. This practice addresses the need of the post-operative child to have a calm and quiet environment. To avoid undue excitement, and to co-operate with post-operative treatments. The involvement of parents is encouraged during this time.

7:3 The nature of the surgical procedure.

A brief outline of the ear, nose and throat procedures performed is offered to facilitate insight into the priorities of care which are unit policy in the area studied and to portray, albeit in a limited sense, the physical dimensions of the surgical treatments.

Tonsillectomy and adenoidectomy are the most commonly performed surgical procedures for children in Britain. Kaiser, (1932) began his pioneering work which studied the rationale and sequelae of adenotonsillectomy. The criteria for performing the operation was challenged as being overly liberal. Haggerty, (1973) concluded from studies conducted in North America, that only 2-3% of the children who underwent removal of tonsils and adenoids actually required the operation. Heggerty then went on to produce some alarming statistics indicating the hazards of the surgery. Schulman, (1970) cited the turbulent emotions experienced by parents following their decision to elect to have their child undergo the surgical treatment. Inevitably, the parents refer to the very small incidence of complications, (there have been no incidence of mortality reported from the area of the study during the past ten years. The incidence of morbidity is lower than the average.) when faced with this procedure in their own child.

Currently, there is a more critical appraisal of the necessity of the procedure and paediatric surgeons follow clearly defined criteria for the selection of children for surgery. The guidelines laid down by the medical professional bodies, (Royal College of Surgeons of Edinburgh, Department of Child Life and Health) suggest specific criteria which were followed by the surgeons conducting the operations in this study. These are:

- i) Children under 8 years who have repeated proved episodes of bacterial tonsillitis over the course of the preceding year are considered for surgery.
- ii) Children of any age who suffer recurrent middle ear infection with threatened deafness, should undergo removal of adenoids only, with the possible requirement for drainage to the middle ear.
- iii) Children of over 4 years with persistent nasal and pharyngeal obstruction and clearly evident enlargement of tonsils and adenoids should be placed on the waiting list for the combined procedure.
- iv) No child under the age of two years should require the removal of tonsils and adenoids, and the combined surgery should not be performed in children under 4 years.

The waiting list in most paediatric ENT units is between 4 and 9 months. (Health Service Audit, 1990). Within the study hospital, the waiting list is currently 6 months. The experience of the child admitted to the specialist unit is generally one of recurrent infections and subsequent absences from school. The parents perceive these episodes of infection as interfering with the child's normal growth and development as well as causing discomfort to the child.

The child enters hospital the day before the procedure feeling well and infection free, this is in fact a key pre-requisite to surgery. He experiences pain and discomfort after the operation and has difficulty in the early post-operative days with eating and drinking. The child leaves hospital suffering from the lingering effects of the anaesthetic and surgery, that is feeling tired and apathetic as well as experiencing sore throat and ears. The physical symptoms generally subside within one week, the child is kept away from school or other large groups of children for a two week period. Post-tonsillectomy infection may develop either in the ears or in the throat and in the latter, is a potentially serious complication that may lead to secondary haemorrhage which necessitates further surgery. The psychological sequelae are the subject of the present research.

Paediatric Anaesthesia.

Few studies have been conducted on the reactions of children to loss of consciousness. The few available studies indicate that pre-school children in particular react adversely to the strangeness of the anaesthetic induction area and the operating room. The absence of mother is documented as being the greatest factor causing the distress (Vernon, et al, 1967).

Bothe and Galdston, (1972), noted difficult inductions in 14% of children age 4-14 years, the difficulty being defined as loud crying, physical resistance and excited or delirious emergence. Although this response is undoubtedly influenced by the type, timing and amount of premedication, the approach of the anaesthetist, the preparation of the child as well as his developmental level, past experiences and present adjustment are also important. The work of Jackson (1951), is still applicable today. Jackson set up a support network for pre-operative children, which included personal contact with the anaesthetist before the operation, a non-threatening visit to the theatre and a calm and unhurried approach to induction, which was conducted in mother's presence. This is the approach used by the consultants in the present study, except, as indicated earlier, parents are not permitted to be with their child during the event. Vernon also showed that the incidence of post-operative vomiting, the need for potent analgesia, and the presence of aggressive behaviour following surgery was reduced if mother or father was present during the child's induction. No replications of this study have been conducted in this country. However, clinical observation of the above behaviour and symptoms is common place during the immediate post operative recovery period in the area of the present study. Research would require to identify and control for the many confounding variables, before any statement could be made about the absence of mother at this time.

The considerations outlined above apply not only to the psychological well-being of the child, but also to the margin of safety. Janis, (1958) in his now classic study suggested some anticipatory anxiety with appropriate preparation may be beneficial in coping with surgical procedures. However, as reviewed during the course of the literature review, marked anxiety, quite apart from the emotional sequelae, may also raise the sedation or anaesthetic threshold, while at the same time reducing the margin of safety. (personal communication from the consultant in the pilot study); Prugh (1983) comments that the percentage of children who have continuing responses of an emotionally traumatic nature is hard to estimate, although the author goes on to quote anecdotal reports and retrospective studies which together suggest that the incidence of adverse emotional reaction to anaesthesia is at least as high as that of responses to hospitalisation. The present study does not intend to discriminate between the effects of hospitalisation and the effects of the treatment *per se*, but accepts that there is an inevitable overlap in stress arising from each experience.

7:4 Administration of Data Collection Instruments.

The pilot study was conducted in the Spring of 1990 and completed within four weeks. Time for reflection and implementation of the issues arising from the pilot work, together with the planning stages necessary for the main study then followed. Data collection for the substantive study commenced in the Summer of 1990, this was completed within four months.

As soon as the researcher received information from the ward secretary that random selection from the waiting list had taken place, and further randomisation had assigned one experimental and two control groups, the researcher then contacted each of the ninety families, providing them with information about the research and inviting them to take part in the study. Formal agreement to participate in the research was signed by the parent, this being a pre-requisite to all clinical studies. The pre-admission questionnaire was then sent to all respondents, and the diary to the thirty families who would make up the second control, with the request that the parents should bring the information on the day of the child's admission to the ward. The secretarial staff were then responsible for sending out the invitations to the experimental group, visits being planned to take place 4-6 days before expected admission.

The researcher was not involved in the conduct of the experimental intervention, although feedback from the nursing staff was regular, this was of an administrative nature since it remained important to assess the level of input from the staff and to respond to any difficulties. In the event, the intervention proceeded smoothly, all parents invited, brought their child along to take part in pre-admission preparation. It is felt that the timing of the letters of invitation pre-empted requests by parents to bring their child to the ward for a pre-admission visit. In the event, two parents who were not included in the experimental group did telephone the ward to ask if they may come for a visit. This group were not included in the study, since it was felt that parental motivation to prepare was explicit, thus introducing group differences which may have acted as a confounding variable.

The researcher spent each admitting day in the ward, this varied from between six and nine hours on two occasions each week during the four month period of the main study. In addition, a further two visits weekly were made to uplift the observer ratings of behaviour which extended beyond the day of admission. The research timetable was necessarily hastened as a result of health board policy changes announced to take place at the end of the year in which the study was conducted, also it was important to avoid planning research during the peak holiday period, when many parents postpone

admission and other children are called without opportunity for preparation.

7:5 Timetable of the Research

Many factors operate as necessary delimiters, when the researcher plans to study a clinical area. The factors which required consideration, for example, permission from the Ethics Committee as well as discussions in relation to negotiating access, were all time consuming and essential pre-requisites.

In addition, the present study required to address the implications of new socio-political policies in relation to health care provision within the specialist area studied. In effect, the basic philosophy which underlies current paediatric health care provision within the health board area, was brought sharply into focus. Little discussion with professionals and parents were forthcoming, therefore the health board remained unchallenged in their policy of removing all five year olds from the ENT speciality within the Sick Children's Hospital to an adult hospital to be cared for within an adult ward with paediatric beds. (The area of the pilot study) The motivating force being the health boards current budget crisis and subsequent response by cost containment. (Lothian Health Board, Putting Patients First, 1990) The threat of the transfer of all school age children to an adult specialist area, carried with it clear implications for the present study, as well as having a major impact on the philosophical basis which underpins paediatric practice. In the event, the changes were postponed until well after the data collection phase of the research.

Attention now turns to the ethical issues raised by data collection within a paediatric hospital. The rights of the child will be addressed within the context of informed consent and human rights.

7: 6 Ethical Issues.

The conduct of research with child subjects has received little attention in the research literature, although the issue has been addressed in relation to the paediatric nursing, from the perspective of quality and standards of care. The rights of the child in the context of nursing research is protected. The philosophical standpoint of the professional bodies, (Royal College of Nursing; Association of British Paediatric Nurses; and the Standards of Paediatric Care, RHSC. Edinburgh) is respected.

The principal ethical considerations in this study relate to the research design used.

Random assignment of children to experimental and control groups raises the ethical dilemma of denying a group of children a potentially beneficial intervention, or conversely, involving a group of children in a pre-admission intervention which may raise their level of anxiety prior to admission.

This study sets out to test the efficacy of an innovative approach to the preparation of children and their parents for the stress documented as being inherent in paediatric hospital admission and surgery. Randomisation is thought to be an effective way to achieve validity. A key concept in this study is that nothing is being taken away from the control group of children, who receive standard hospital preparation, while an additional approach is added to the preparation for the experimental group.

As well as securing the informed consent of the families involved, it is important in a paediatric clinical study to enlist the co-operation and interest of the professionals who will be involved in the experimental treatment. The consultants in the ward, both expressed their interest and offered full co-operation with the study, which they perceive to be an important dimension of nursing care within a specialist unit. Similarly, the nursing staff enthusiastically assented to the intent and philosophy of the study and co-operated fully with the process of the research. The researcher in turn has a commitment, within this conducive climate to ensure that the research is conducted in an efficient and unobtrusive manner and has an obligation, not only to the families, but also to the professionals, to communicate the findings. The discussion of the process of conducting nursing research is a most effective way to facilitate research within the profession. When this is done at a clinical level, the perceived relevance of such initiatives is more apparent. The appropriate ethical consent for the present study was obtained from the Paediatric/Reproductive Medicine, Ethics of Medical Research Sub-Committee.

All persons regardless of age, degree of relative freedom, or mental capacity, have rights that must be protected when they are serving as research subjects (Lynn, 1986). Although many writers prefer to refer to children's interests rather than rights for reasons of definition and proxy consent, (Alderson, 1990), this writer asserts that children enjoy the same 'rights' as the rest of mankind. These rights, the rights of informed consent, confidentiality and anonymity of data, privacy, the right to withdraw without recrimination and protection from harm have been explicated in recent years. Davis, (1979) cites three principles which are fundamental to these rights that provide an ethical basis for research involving human subjects. Derived from the National Commission, (1979) these principles are:

- **Respect for person.** This includes the conviction that individuals are and should be treated as, autonomous. Also, when the person has diminished autonomy (with reference to the accepted adult criteria) he or she should be protected. The specific dilemma in relation to research in young children is that the parents take control and in effect make the decisions on the part of the child. The researcher then has the responsibility to ensure, not only that the rights of the child are protected within the context of the research, but that the parental perspective made on behalf of the child is appropriate. The present study applies the principle of informed consent, given that the legal guardians will respond on the child's behalf. In addition the researcher asks each child if she/he would like to take part, given that the information is presented in a developmentally appropriate manner.

- The obligation to do no harm as well as to maximise the benefits received, involves the nurse researcher in planning and developing an intervention which is based on the application of sound principles of child development. In addition the commitment to disseminate knowledge gained as a result of the study is an important part of the process of research. This will be discussed in the final chapter.

- The principle of Justice is incorporated in the ethical code, this addresses the presence of vulnerable groups in the community, and specifically highlights the problem of pockets of the community being over-subjected to research. This is largely protected by the presence of ethics committees in most specialist settings, for example, education, health, social services, prison authorities, all have formal procedures which serve the purpose of protecting such groups .

The United Nations Convention on the Rights of the Child (1989) expressed, as an overriding concern, the issue of dignity. Respect for the dignity of children is considered by the signatories of the Convention to be "consonant with provision of those elements important to their growth as full members of the community" (Article no. 44/)

Within this document, the disparate perspectives on children's rights are integrated through a focus on respect for the dignity of the child. By confirming the child's experience, the Convention makes clear that children are to be taken seriously as persons. In defining the boundaries of fundamental human rights, Melton, (1991) uses as its foundations those interests that are phenomenologically most important to personal dignity. A developmentally sensitive approach to children's rights ensures both that those interests essential to the dignity of human beings in general are recognised for children , and also the specific and unique rights of a dependent person.

As Pringle, (1980) comments;

Children inevitably depend on others for their well being, care and education. they have no vote or voice in the running of the community... resources devoted to them are societies investment in tomorrows parent.
(p.96)

Children have the right to data being treated confidentially and anonymously when disseminated to others. The present study, as a result of expressed anxiety by some parents in the pilot group, required the researcher to spend some time reassuring parents that the data collected was for the purpose of the research study only and the information given by parents, would neither be seen by the ward staff nor would it be filed in the case records. Clearly all parents were asked if the information could be used by the researcher in a variety of settings including publication in nursing journals, when the outcome of analysis was known. All parents consented to this with the reassurance that pseudonyms would be used. The children were asked if they would mind sharing their experiences with me during their time in the ward, and when they went home, again a positive response was made.

The clinical area, as a 'real life' laboratory presents a situation where the ideal of human rights and protection is "more illusive, less exact and more difficult to maintain" (Zelizer, 1985). The nurse researcher operating within this context respects not only the code of practice outlined above, and that of the professional bodies in the specific area researched, but also, remains aware of the privileged position offered when permitted access to the deeply personal experiences explored during the process of the research.

The sampling process as it applied to the present investigation is now discussed.

CHAPTER 8.

THE SAMPLING PROCESS.

8:1 Criteria for selection of the sample.

In selecting an appropriate sample, the fundamental emphasis of the present study, that is *preparation* for paediatric hospitalisation, clearly required that the sample should be children who were scheduled to undergo elective surgery.

The population are children on the ear, nose and throat waiting list of a Regional Sick Children's Hospital. The sample chosen from the target population being randomly selected. The detail of random sampling is as follows. Children are randomly selected from the waiting list by adopting a sequence of selecting 1/2 and 1/3 - in rotation. This approach was conducted by the ward secretary following training given by the researcher. Further random sampling then took place to assign the groups. This procedure was achieved by adopting a table of random numbers. The number of admissions during any given week vary considerably. During the period of data collection, the average number of children admitted weekly for similar procedures was 25. This lower number reflects the cancellations or postponements during the peak holiday period. Using the above criteria of randomisation, an average of ten children were included in the study each week. Admission interviews were conducted at a convenient time during the admission procedures and generally lasted between 15 and 35 minutes. The length of each interview was dependent on the individual respondent, this in turn being indicative of their perception of the research interview as a facilitative forum. Issues of validity will be re-addressed during presentation of the parent's analysis.

The need to control for factors other than those which may influence child and parent responses, for example, the nature of the objective stress, length of stay, pre-hospital adjustment, previous hospital care and so on, necessitated selecting a sample of young children who would essentially experience similar surgical procedures.

The children in the sample all met the following criteria:-

- Age range between 3-7years. This reflects the peak incidence of admission to Sick Children's Hospitals in general and to ear, nose and throat units in particular. Clearly, the wide age range selected presents age as a key variable. As can be seen from a review of

the current literature, most research concerned with children in hospital has concentrated on young children, the majority being under 5 years old. This carries the implied assumption that since older children less often exhibit overt signs of upset, they are not experiencing upset. (Harris,1979) This assumption has been challenged by Clough (1979) and earlier by Moncrieff (1957), who writes:-

“Age differences in psychological response may reflect differences in modes of expression, rather than differences in the extent of distress.” (p.86)

Clough, (1979) further cautions:

A proposition which starts as an indication that certain age groups are more vulnerable than others to a stay in hospital, can turn into a hospital policy that those under five can be visited freely, but others may not be. (p19)

The present research design addresses these differences in response while accepting the similarities in terms of emotional support and care, as empirically reviewed by numerous studies, (Hall and Stacey,1979, Peterson, 1989). The decision to select the age range studied was made on the grounds of securing a sample at widely disparate levels of cognitive and emotional development, while being representative of the children most frequently admitted to the unit.

- The children selected are free from any chronic disease or medical or psychological condition requiring special care. The theoretical assumptions underlying this requirement (and discussed during the course of the literature review) relate to the potential effects of previous medical and social stressors of sufficient import to be considered significant in medical, educational or social terms. The literature is equivocal in relation to the effect of past stress on subsequent exposure to a stressful event. In Rutters' (1987) view, the 'steeling' effect of a stressful experience may prepare the resilient child to cope more ably with future stress.

However, the converse may apply in that the expectation of distress may heighten the anticipatory worrying (Janis, 1974) and in Bibace and Walsh's (1980) terms increase the level of helplessness as control over the situation is not expected, therefore not attempted. Within this conceptualisation, previous exposure to stress serves as an additional coping burden and expectation of subsequent stressors as negative experiences.

- The sample are admitted for similar procedures. That is tonsillectomy, adenotonsillectomy (removal of adenoids as well as tonsils) myringotomy with or without insertion of drainage tubes (aspiration of fluid from the middle ear). This latter procedure

is frequently combined with removal of adenoids. The nature of the post-operative discomfort and distress experienced by the child which is known to be, or expected to be attributable to the procedure performed is an important variable. For example, it is expected that children will experience painful throat following such procedures. The pain is controlled and of short duration for the majority of children. Post operative care within the speciality is standardised, varying only in doses of analgesia administered and frequency of administration, which in turn is dependent on the nature of the procedure (children undergoing tonsillectomy receive regular analgesia for at least the first 12 hours post-operatively) as well as the pain control needs of the individual child.

- In fulfilling the third sampling requirement, the fourth is also secured; that is, the operations are elective and the period of in-hospital care is similar for each child, that is 2-3 days.

The elective nature of the surgery is an important factor. It was important in this study, to avoid studying the process of adjustment within a crisis laden environment, for example, a general surgical/medical ward where children are frequently admitted as emergencies with the concomitant heightened anxiety and professional activity.

- A final sampling criteria relates to the minority of children who do not progress uneventfully. Children who develop immediate or secondary post operative complications, (i) will be treated as a distinct sub group within the study. Although rare events, the presence of such complications would clearly change the nature of child and parent experiences.

Random assignment to determine the experimental and control groups is applied following random sampling from the waiting list. Both procedures were performed by the ward clerkess normally responsible for organising admissions to the unit but who had no knowledge of control or experimental conditions. Subjects were simply assigned to groups using a table of random numbers, which was used competently by the clerkess after some training by the researcher. Following adequate preparation of secretarial staff, the researcher had no further contact with the assignment of groups.

- i) Post-operative bleeding occurring within a few hours of surgery (Reactionary haemorrhage)
Post-operative infection which develops up to ten days after surgery, may also result in
Secondary haemorrhage, the child bleeds heavily when at home.

The operations were performed within the specialist ear, nose and throat unit of the Regional Sick Childrens' Hospital. Senior consultants conducted the operative procedures on both list days of the week, therefore there was no difference to the sample in relation to the perceived level of expertise of the surgeon conducting the procedures.

8:2 Sample Size.

Securing an adequate sample required addressing the requirements of data analysis within the design selected as well as the practical limitations of time and other resources. Also the sample had to be large enough to facilitate statistical analysis. Since the power of such an analysis is associated with the expected effect size as well as the sample size, increasing the sample size will also increase the size of the effect thus making it more likely that the effect of the experimental intervention will be statistically detected. However, a balance required to be drawn between the need for methodological rigour which included assignment of a second control group in an attempt to minimize the 'Hawthorne' effect, but subsequently diluting the the overall sample size, and the need to achieve a statistically credible analysis. A further limitation to sample size is the current policy of the health board in relation to the care of children within this speciality. This policy, implemented as a result of imposed financial constraints on the health boards, necessitates relocating children over 5years to the adult ENT unit within the city.

This change in direction and philosophy required the researcher to complete data collection before major changes were introduced.

Data collection therefore took place over a four month period. The study children were admitted to hospital in groups of 6-14 on average.

The variations were due to the inevitable cancellations, usually at the last minute, and were the result of recurrence of upper respiratory tract infections, or varying social reasons. Children who had been included in the initial sample and later cancelled admission, were not included in the study during their subsequent second appointment to attend. It was felt that the effect of the child and parents' 'false start' would influence subsequent preparation at home and adjustment during the admission. (personal communications with parents, observations during many years of clinical experience) This group of families would provide a fruitful avenue for further study, since no empirical data is available which examines this important phenomenon.

Ninety children and their parents were selected from the waiting list and further random sampling assigned thirty families to each of the three groups.

Following phase 1 of random sampling, all parents were sent information about the study and were invited to participate (see appendix 1). Informed consent was obtained. The first research instrument was then mailed first class to the entire sample, accompanied by further information about the study, in particular emphasis was laid at the outset, on the importance of the final questionnaire. A contact number was given, parents were invited to telephone the researcher if there were any queries concerning the study. The ward telephone number was also appended to facilitate enquiries relating to the child's admission.

8:3 Respondents.

The respondents in this study were principally the mothers, that is 88/90 . This is an expected finding in child care research and reflects societal definitions of the maternal role as much as the availability of paternal involvement. This issue is discussed during the course of the literature review. Two fathers acted as respondents, the key characteristics of their responses, where significantly different from the maternal responses, are presented in association with the variables of interest. It is however, important to note that an additional 35% of fathers accompanied the mother with the child on the day of admission to the ward although, while interested and at times participating in the responses, were happy to agree to the mother being the respondent. This group also envisaged their role as a participant one in relation to the care of the child in hospital, whether this be in relation to caring for the siblings at home, or sharing the care of the hospitalised child with the mother.

8:4 Significance

The issue of whether a finding is significant can be addressed in two distinctly different ways. From the statistical standpoint, the question of significance refers to whether the observed change was due to a chance variation or to the intervention efforts of the investigator. In determining a level of significance, the researcher must decide at the outset how willing she/he is to conclude that a hypothesis should be rejected when that might not be the correct decision, that is, the level of significance is considered to be the likelihood of an erroneous hypothesis rejection. The figure that represents significance is dependent on sample size and nature of the research undertaken. Clearly, in clinical

intervention studies which have implications for the treatment and or subsequent outcome of a disease, for example in the widely used clinical drug trials, then levels of significance (.001) represents a very small willingness to reject an underlying "true" hypothesis that should not be rejected. That would result in a level of confidence as great as 99.9% in the statistical conclusions reached. However, this level of significance is rarely warranted in most nursing research studies (Lynn,1990), although a scientifically credible alternative must be applied. The present study selects *alpha* 0.05 given that the overall sample size is small $N=90$, and the nature of the experimental intervention does not carry life threatening implications for the respondents. Statistical significance is a dichotomous variable rather than a continuum; a result is either significant or it is not.

An equally important consideration requires to be addressed. That is whether the observed change is socially significant (Baer, Wolf and Risley, 1968). Assuming that prior to the intervention the preparation approach was inadequate to all, then the researcher would not consider the change to be significant unless the outcome criteria - that is satisfaction with and perceived benefit from preparation of the treatment group on an individual basis, was viewed as a positive experience by that group (since they would not have been exposed to standard preparation therefore could not compare). Thus three distinct possibilities emerge within the experimental control conditions. One is that the investigator can produce a statistically significant change that is also socially significant. This would involve the experimental group reporting and being observed to display less stress and anxiety, as defined in the research tools. The second possibility, is that the change is not statistically significant but is socially significant, for example all parents make explicit their very positive views about the experimental treatment and indicate a beneficial effect of this treatment on their child's adjustment to the stressful events, as reported on the PHBQ.

The final possibility is that the intervention effects may be statistically significant, but not socially significant. For example, the parents and children demonstrate fewer stress related symptoms but do not identify the experimental treatment as being of responsible for this less stressful experience. For example, this situation may occur when parents have high expectations of the event and expect preparation to be an integral part of it. Ideally, the effects of the intervention should be both statistically and socially significant. In fact, many studies in behavioural paediatrics do not meet these two criteria (Karoly et al, 1982). In clinical practice however, social significance is an important issue. Karoly, makes the salient point that a treatment effect which is perceived as being beneficial is more likely to carry positive longer term effects. Indeed, how children cope with subsequent medical and social stressors is frequently a function of how past stressors

have been perceived (Rutter and Garmezy, 1983).

It is appreciated that the findings of the present study can be generalised only to the accessible population from which the sample was drawn, before random assignment to groups; that is only to children between the ages of 3-7 years who are on the ear, nose and throat waiting list of a Sick Childrens' Hospital. However, as Woolgar (1988) points out, when the purpose is to develop a causal theory, the most important element is to secure random assignment to reach a valid statement about the effectiveness for the subjects studied. Further research would look at the generalisability of the study findings to other paediatric populations admitted to hospital for elective surgery (a measure of external validity), since the nature of the objective stress is considered a key variable in the present study.

8:5 CHARACTERISTICS OF THE SAMPLE.

$N = 90$

Experimental group	30
Control i	30
Control ii	30

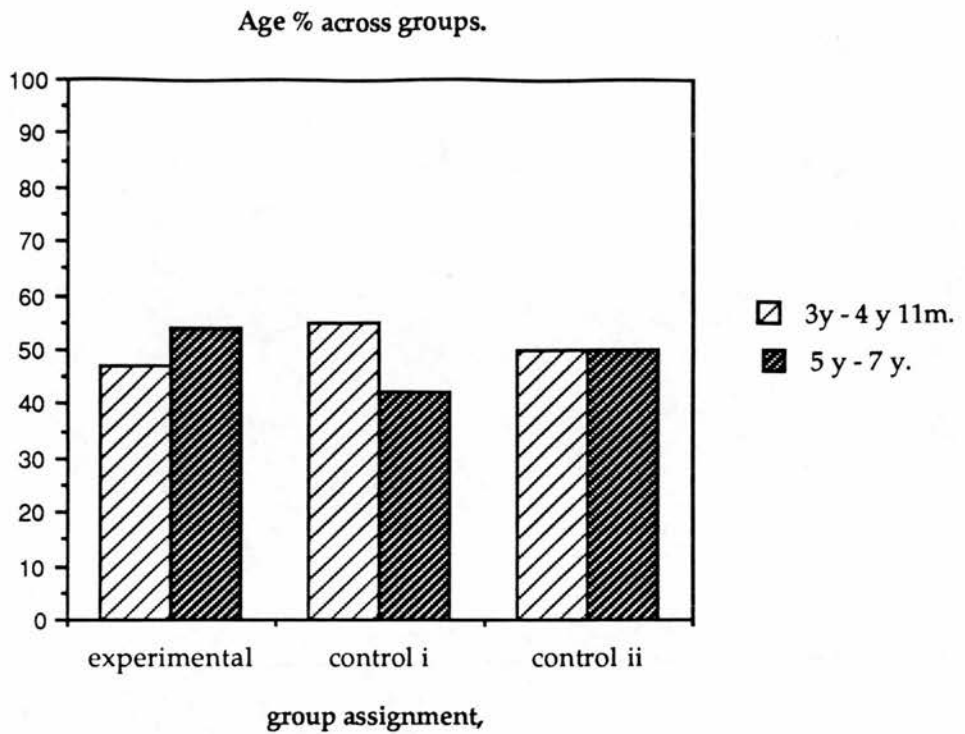


Figure1. Percentage of children of different ages across groups:

Mean age of groups = 4.46

Std. Dev.= 2.11

Both age groups are reasonably distributed in each of the three groups. It is observed that control group i has a marginally higher number of pre-school children. The literature contends that the younger age group are expected to experience greater difficulty during the stressful experience. In addition, pre-school children are reported to require a longer period of adjustment following such an event.

2. Group Assignment by Sex

Table: 1.

<u>Group</u>	<u>Male</u>	<u>Female</u>
experimental	14	16
control i	10	20
control ii	17	13

Group by sex.

It is apparent that control group i is less well balanced than the other groups, twice as many more females than males in the attention control sample.

3. Social Class

Social class groups were assigned according to the Registrar General Guideline's (1980), the groups were then collapsed to afford some clarity and economy in presentation; that is:-

Social class 1 stands alone, that is as derived directly from the raw data.

Social class two, includes non -manual from class three as well as professionals

Social class three, depicts all manual category within this class

Social class four/five, includes those assigned to this class as well as class five.

The above social class groupings are assigned on the basis of previous empirical studies conducted within health care settings (McHaffie,1988). Non-manual categories are grouped with professionals since studies have indicated that the parental involvement in the child's care during hospital treatment is more evenly distributed across professional and non-manual groups than across non-manual and manual categories (Robinson, 1979, Hall, 1987, Stacey, 1990). Social class variables as they pertain to health care generally and specifically to sick children are discussed in chapter 3.

A fair distribution across groups was secured as a result of random sampling, although it is noted that control ii have a higher number of class three, (manual) within the population.

Kruskal-Wallis one way analysis of variance was applied to the social class groupings:

<u>Mean Rank</u>	<u>Group</u>
41.10	Experimental
45.20	Control i
50.20	Control ii

chi-square = 1.82 $p = NS$.

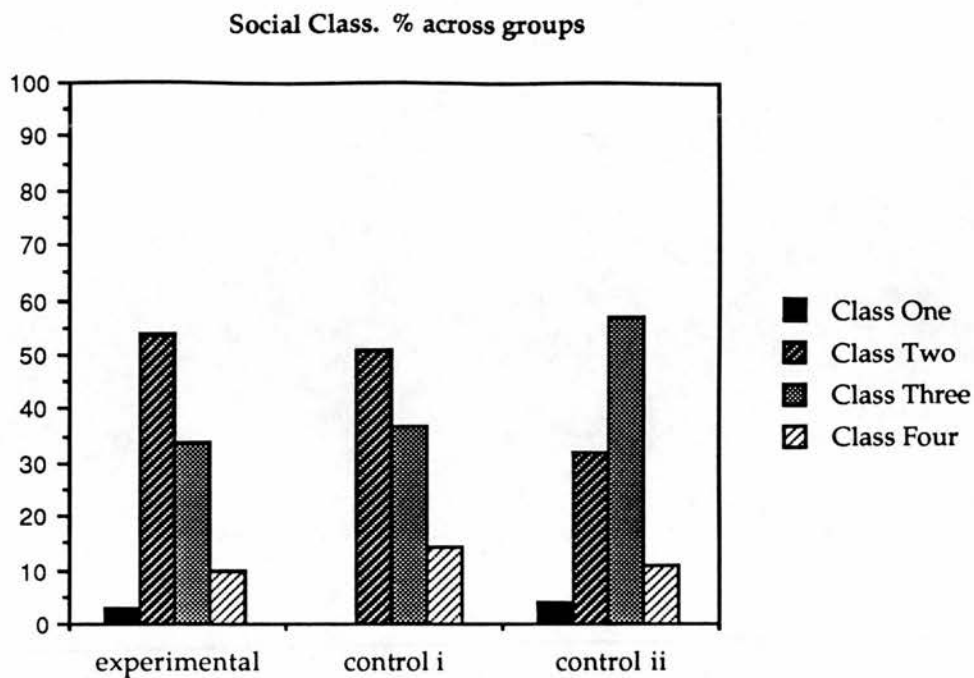


Figure 2. Social Class across groups - Percentage.

It is noted that control group ii has a higher number of social class three within the group. Further issues concerning social class require to be addressed. In particular, there is some difficulty in categorising social class, especially in relation to families of divorce when the mother is economically active.

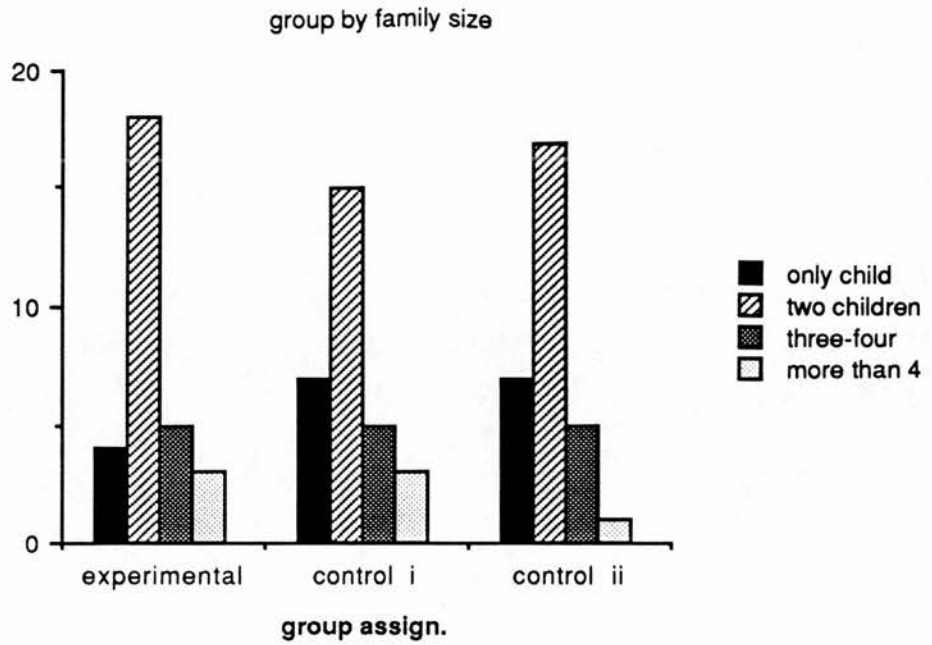


Figure 3. Family Size Across Groups.

chi-square = 0.89

$p = NS$

Having addressed the sampling process applied to the present study, attention now turns to the analysis of the data collected. Analysis will be presented as two chapters, which is intended to enhance the pursuit of clarity and specifically *not* to suggest an artificial distinction between the quantitative and qualitative data. An integrative discussion will then ensue as a synthesis of the positions offered is explored.

CHAPTER 9

ANALYSIS AND PRESENTATION OF THE FINDINGS.

SECTION 1

THE QUANTITATIVE DATA

9:1 Introduction.

This section is concerned with the analysis of the quantitative data which are derived from the five research instruments used to gather data throughout the process of the child's admission and surgery.

The first part of this section deals with the sources of data specific to this quantitative analysis. A full discussion of the instruments is presented in chapter 5 and may be found in the appendix. **The second part** is concerned with the conceptual development of the sub-scales applied to this analysis. Discussion of how the data were organised and subsequently aggregated to form summary scores is presented. A rationale for the use of summary scores is discussed with reference to the developmental literature.

Part three presents the approach to analysis applied to the quantitative data. Discussion of the analytic procedures, their strengths and limitations will be reviewed.

The findings are then presented in the following temporal sequence:

- a) The pre-admission data relating to child and parent variables is presented.
- b) The outcome measures reflecting the effects of the experience on child and parent are presented.

Part four of the quantitative section is concerned with a discussion of the findings and their influence on the subsequent qualitative analysis to which the next chapter is devoted.

9:2 Data Sources.

The data discussed in this section are derived from the following five sources:

1. *Pre-admission questionnaire, this was received by each of the 90 respondents seven days prior to the child's admission to hospital. Parents were then requested to bring the completed questionnaire to the ward on the day of admission. (N=59)*

2. *The Admission schedule. Data gathered during a semi-structured interview during the process of the child's admission to the ward. (N=90)*

3. *Parents responses, elicited at a convenient time during the day of the child's admission. These comprise the GHQ-12 (Goldberg and Williams, 1986) as well as the use of open questions designed to tap parental feelings in relation to the ensuing events, the latter data will be explored during analysis of the qualitative data. (N=90)*

4. *Child responses to the events which represent maximum stress points during the experiences which comprise admission to hospital and surgical treatments. (N=90)*

5. *Post-hospital outcome measures. These comprise the 27 item Post-Hospital Behaviour Questionnaire as well as post outcome responses, elicited from parents as open questions. These open questions, which form an integral part of the qualitative analysis, specifically ask about satisfaction during the process of the child's experiences as well as parental attitudes towards that process. (N=90)*

Discussion of Data Sources.

In total, the five questionnaires which were administered to each respondent produced one hundred and thirty four variables. The sixth questionnaire, the pre-admission diary (additional attention given to control group ii) is discussed briefly in a later section. Data is therefore presented from three subsets, that is two control groups and an experimental group, that is 30 in each group. (N=90)

Some items on the pre-admission questionnaire show a limited response rate (N=59 = 63.3% group response:- experimental=26, control i=14, control ii=19), this limitation was due to some parents inadvertently leaving the questionnaire at home on the day of the child's admission. Other items on this document; that is, those considered to be central to an understanding of the *process* of preparation and to a reasonable pre-admission profile of each child, were asked again at the point of admission and therefore have the maximum response (100%). All other questionnaires have a full (100%) response rate.

The strategies employed in this study to maximise mailed questionnaire response also contributed to the high response rate. These points are discussed in an earlier section of this thesis.

The quantitative data presented in this section begin to address the effect of the experimental intervention. The measures adopted to explore the relationships between the intervention and the stress experience in this section, are generally assigned scores which are specific to each instrument. A high score on these summary scores represents 'poor' adjustment, while a lower score is representative of a 'better' adjustment on the variable. In addition, the 'blind' observer ratings used in this study have been subjected to inter-observer checks and have attained a high level of reliability (92%). These issues are discussed in detail in a preceding chapter.

9:3 The Conceptual Development of the units of Analysis.

Summary Variables - A Rationale.

From a total of 134 items derived from the five research instruments, some measure of control was imposed by compiling summary scores. Selection of summary scores was informed by a review of the developmental literature and based on empirical observations of children's responses in a variety of settings. (La Montagne and Hepworth, 1991, Kagan, 1983). The choice of a logical approach to analysis was also based on the clinical and teaching experience of the writer. Past experience confirms the need to apply this clinical knowledge to the development of a comprehensive yet concise account of the many issues which combine to influence the adjustment of the child and his parents to the experience of paediatric hospitalisation and surgery. The application of summary scores as an analytic tool contributes to this aim. While this may be a common approach in sociological and education studies, no previous nursing investigations have, to the best of my knowledge adopted this approach.

Composition of Summary Scores.

A discussion of the logical and conceptual process which resulted in the development of the composition of summary scores is now presented.

Collating summary scores involved identifying those items which represented the same construct for example, the child's responses to previous stress, his pre-admission demeanour and so on as follows:

1. Variables relating to the child's reaction to previous stresses included data on reaction to medical and dental settings, as well as specific data on the child's coping responses with previous stress. This summary variable then combined three single items. These items represented an important component of the pre-admission profile of each child in relation to the research question which asks about the influence of preparation for a stressful event, on the subsequent responses of the child.

This summary variable serves as part of the pre-admission profile and is therefore not influenced by the experimental treatment.

The literature review supports the position that attention should be given to those variables which influence the child's perception of and subsequent coping with stress (Melemed and Seigal, 1984). The key factors, are the child's age and past experiences of stress. Up to one year prior to the event is selected, since major trauma, for example, family separation, divorce or bereavement characteristically requires a protracted period

of adjustment, although it is accepted, that other events of significance to the child, for example loss of a pet, may well have been overlooked by the adult respondent one year on.

The *nature* of the events is discussed in the qualitative analysis in relation to parental perceptions of past stress and subsequent coping by the child during the present stressful experiences.

2. *Consideration of the issues surrounding family coping and adjustment* prior to the child's admission led to the formation of a summary variable which combined arrangements for sibling care, visiting arrangements and work commitments of the parent. The experimental intervention, which took place 2-6 days prior to admission, is thought not to influence this summary score.

3. and 4. *Attention to the pre-hospital demeanour of the child*, collated information relating to the child's level of attachment behaviour, or to his autonomy and social behaviour, a further two summary variables were then formulated, these formed part of the pre-admission profile of each child and were not influenced by the nature of preparation for hospitalisation.

The pre-admission data elicited a profile of the attachment, autonomy and social behaviour of the child under 'routine' conditions. The rationale for the development of items into a summary variable representative of attachment and social behaviour was made with reference to the selection of a conceptual analysis drawn from the developmental literature (chapter 3). Extensive review of the developmental literature failed to find an instrument which would serve the purpose of sampling the attachment and social behaviour of the child prior to a stressful encounter. Opportunity to further refine and develop the instrument devised for this study to contribute to this important area, is a potential development of the study. A further important guide to the selection of summary scores was the nature of the experience studied. For example, dependent and fear related behaviours within the context of hospital admission, represent those behaviours itemised in the developmental literature as being representative of attachment as well as specific context related behaviours. An example is the sleep behaviour of the child, which in a hospital environment is known to be closely related to attachment (Brown, O'Keefe et al 1979), or the response of the child to parental absence, again a developmental issue.

Pre-admission data provided a dual purpose of affording a base-line comparison which could then be compared with the post outcome measure, and also identifying those children who were outwith the range of expected behaviours for the given developmental stage. This finding

would clearly influence the child's response to the stress of hospital.

5. *The pre-admission coping of the child in relation to the manifest anxiety* observed by the parent and the behaviour subsequently displayed by the child *after* he knew about the forthcoming admission. This summary score was derived from the sum of the items which represent the child's adjustment during his daily routines in the week preceding admission. The effect of the experimental treatment, which took place 2 - 6 days before admission is considered within this summary score. The literature addresses the influence of the initial responses made by the child in shaping his reaction to the forthcoming events (chapter 4).

6. *Parent coping as assessed by the GHQ-12 was measured,* The findings of the GHQ-12, which is one measure used in this study to tap parental anxiety prior to the child's hospitalisation and surgery provided a logical parent coping summary measure. The effect of the experimental intervention is examined in relation to this outcome summary.

7. *Manifest upset and co-operation ratings of the child's in-hospital adjustment* produced summary scores of value when looking at the overall coping during in-patient care. This also forms an outcome measure and the effect of the experimental treatment is examined in relation to the child's responses during the period of in-hospital treatments.

Blind observer ratings of manifest upset and co-operation were made along a five-point scale (Wolfer and Visintainer, 1979.) This was later collapsed to three response categories as a result of relatively empty cells when the chi-square test was computed. The extreme responses were noted prior to collapsing the categories.

The items included within the manifest upset and co-operation ratings were selected as being representative of maximum stress points during the in-patient experience. These are contained within instrument no.5 (appendix 1.) The rationale for the selection, together with an account of the scoring criteria is offered in the methods chapter.

The above items were aggregated into a summary score, after consideration of each individual item was made, and cross-tabulated with the identified confounding variables. For example, previous experience with stress, age, parents approach to preparation and social class. The influence of the relevant variables will be discussed in the following section when the significant individual items will be presented during an integrative discussion of the findings.

8. *Post - outcome measures, reflecting the child's overall adjustment*, were collated to form a summary measure of post-hospital behaviour change.

The Post Hospital Behaviour Questionnaire (PHBQ) is the cornerstone of the post hospital outcome measures. This instrument asks the parents to recall the child's pre-hospital demeanour and compare it with the present (post hospital) behaviour. In addition, how the child coped overall with the hospital experience, both emotionally and physically is asked as a semi-structured question (Qu. 16, appendix 3). Also, reaction to returning to normal day to day activities after the event is of importance when assessing the child's post-hospital adjustment, coping with return to school or nursery is therefore reported by the parent.

Parents were then asked to state how their child coped with the experience of hospitalisation and surgery. Three response categories were available (appendix 1). These data are not included within the PHBQ summary variable, since a specific focus was sought, that of parents standing back and assessing their child's overall response to the events as a whole.

A total of eight summary scores were created from the 134 items representing the sum of five research instruments. Considerable care required to be exercised to avoid imposing inappropriate summary variables, that is, rather than impose logic, the logical associations between items were identified, analysed and subsequently summarised to form summary variables of considerable use when focus requires to be sharpened to specific areas of interest.

The following table depicts the grouping and location of items included in the above summary scores .

Table 2 Summary Variables derived across the range of five research instruments.

Summary Variable	Instrument no.	Item no.
i. Attachment behaviours	2	1-16
	3	7,18-23,27,28,31-32,38-39,42-43.
ii. Previous Stress	3	17
	2	8,10.
iii. Autonomy and Social behaviour	3	8-10,24-26,29-30,33-35,40-41.
iv. Family variables	2	23,24,28,29,31.
	3	1,3,4.
	6	7.
v. Child coping pre-admission	2	19,21,26,27.
vi. Parent coping, anxiety pre-admission (The GHQ-12)	4	1-12
vii. Child's in-hospital adjustment	5 (a)	1-5
	5 (b)	1-7
	2	30
viii. Child's home adjustment	6	1-6, 8-28.

Items comprising summary scores i-iv are pre-admission data and are not expected to be directly influenced by the experimental intervention, while items in summary scores v-viii are all outcome measures.

Approach to Analysis

The many variables which potentially influence the child's responses to hospitalisation and surgery are identified throughout this analysis and are discussed in relation to the qualitative analysis in the following chapter. The table below summarises the key variables of interest: A

full account of the variables which influence the child and parent responses to paediatric hospitalisation are reviewed in chapter 4.

Table 3. Child Responses to Hospital - Summary factors of influence.

Pre-admission factors	Factors at the time of Hospitalisation	Post-admission factors
Personality	The nature of the treatments	Overall effect of events
Parent/Child Relationships	Family Support	Post-physical recovery
Previous Stress	Staff/Family Relationships	Parental Care/support
Preparation	Unfamiliarity / Preparation	Parents Concerns-recovery
Parental Anxiety	Duration of the Events	and effect on child
Age /Sex	Age/Sex	Social Class
Social Class		

The table above represents a summary of the key variables which operate to influence the child's responses to the stress inherent in hospitalisation and surgery. While the inter-relationship of all variables is accepted as important, this section will address only those variables which are analysed in relation to the quantitative data, that is preparation for hospital and age of the child. All other variables are considered during the integration of the findings, presented in the next chapter.

Structure of the Presentation.

Presentation of the findings assumes a temporal sequence, that is a logical process representing the stress experience of parent and child as it unfolds across the course of the events. This approach reflects the conceptual model of stress, appraisal and coping which informs the framework of this study (Lazarus and Folkman, 1984) and attends the temporally specific nature of the process.

9: 4 Statistical tests applied to the present data:

Descriptive statistics were applied first to the raw data.

A comparison of the two control groups using the 't' test was then undertaken to assess the value of combining the groups. Some group differences were apparent, for example, parental reports of anxiety and child responses during in-hospital care, therefore the decision to present a three group analysis was taken. Also, it was important to consider group differences across all three groups, particularly in relation to the effect of the experimental treatment.

The principal tool used in the analysis of statistical data was the Statistical Package for the Social Sciences (SPSSX-vol.3.0 1990). The statistical tests selected were non-parametric, appropriate to nominal data. The level of statistical significance adopted for the present study is $p = 0.05$. However, a p value simply states the significance of a variable under study. The finding of a significant value does not necessarily imply causality. Conversely, the absence of a p value does not indicate the lack of clinical and social importance. It is also relevant to state that the sample size of 30 respondents in each of the three groups imposed low power on the statistical tests.

All items across all questionnaires were subjected to chi-square, cross tabulations being applied to examine the effect of the key confounding variables on the responses of each group. Therefore an individual item analyses was examined at the outset of the quantitative analysis. This comprehensive analysis highlighted levels of significance for important individual items, prior to aggregating them into summary scores. This interesting finding can appropriately be addressed during the qualitative analysis when the inter-relationship of key variables, for example, preparation, age, and maternal anxiety will be examined.

The Kruskal-Wallis, one way analysis of variance (ANOVA) is a test that makes minimal assumptions about the underlying distribution of the data, and is used in this study to assess difference between treatment groups. In particular, the Kruskal-Wallis is used to test difference across groups in relation to the summary variables. For example, the study by Eiser (1982), which examined well and hospitalised children's conceptions of illness applied the Kruskal-Wallis to examine the differences in the occurrences of responses to specific health related issues.

A key issue arising from early analyses relates to the number of items of interest. Following the preliminary statistical tests outlined above, it was clear that some control required to be exercised over the large number of items, these items represent different points in time, and reflect responses to differing situations during the experience. This was necessary from a practical as well as a conceptual viewpoint. Handling a large number of variables of interest which are inter-related is not only cumbersome, but also poses an obstacle to the pursuit of clarity. The application of summary scores was therefore made.

Alternative approaches to analysis were considered. These included factor analysis as a way of reducing and subsequently analysing the data, an approach used by the researchers who developed the PHBQ used in this study (Vernon, Foley and Schulman, 1966). The sample size of this study precluded this approach. In addition, a cluster analysis was considered but proved inappropriate to a three sub-set analysis. Similarly, the pre-test post-test approach was considered and rejected on the grounds that the data used in this study reflected the need to

follow the child and parent throughout the process, therefore pre and post admission questionnaire items necessarily differed.

9:5 PRESENTATION OF THE FINDINGS:

The framework adopted for the presentation of the findings is as follows:

The demographic data are presented in relation to the characteristics of the sample and may be referred to in the preceding methods chapter.

The pre-admission scores will be presented prior to turning attention to the outcome measures. The summary analyses will be addressed in relation to the independent variable as well as with reference to the age of the child, which, in developmental theory, is an important consideration

Pre-Admission Data

The pre-admission data (see summary items 1-4 table 2) reflects the base-line profile of the child and family. The child's previous contact with stress across the groups is studied as an index of the possible influence of previous exposure to stress on future adjustment during a subsequent stressful experience.

Pre-admission profiles of each child are built up and reflects the day to day behaviour of the child within his familiar environment during routine conditions. A measure of the child's attachment behaviour is achieved. This measure is recorded across the three groups, and assessed in relation to the age and developmental stage of the child. Similarly a score of autonomy and social behaviour is derived for each child.

The family summary score which condensed items reflecting the circumstances of each family, for example, visiting arrangements, family size, sibling care, the availability of the mother to spend time with her child in hospital and so on are analysed across groups and will be important in relation parental involvement in the child's care and the perceived satisfaction with care which draw on the qualitative analysis.

The following summary scores are presented: K.W = Kruskal-Wallis ANOVA.

Table 3. Analysis of Pre-admission Data - Summary Scores.

	K. W.	Chi-square	Mean	Std. Dev.	P value
i. Previous experience of stress.					
Experimental	44.9		.50	.90	
Control i	42.6	0.8	.43	.81	NS
Control ii	48.8		.56	.73	
ii. Attachment					
Experimental	48.2		3.73	1.04	
Control i	48.9	2.4	3.70	1.20	NS
Control ii	39.3		3.33	1.54	
iii. Autonomy and Soc. Behav.					
Experimental	43.8		2.46	.97	
Control i	47.4	0.2	2.60	.89	NS
Control ii	45.2		2.56	.85	
iv. Family Variables					
Experimental	46.8		3.23	1.71	
Control i	41.8	0.8	3.03	1.92	NS
Control ii	47.7		3.26	1.65	

Discussion of Pre-Admission Summary Scores.

It is apparent that no statistical significance is found within the above summary table. It is also evident that no wide distributions are present. However, the distributions which are observed signal the need to attend to individual case analysis, particularly attachment, which shows a comparatively low score for control group ii. As already stated in an earlier section of this analysis, individual item analysis was performed on all the key items of interest and were cross tabulated with the key variables, for example, age, social class, previous experience of stress. Some interesting levels of significance were found within the individual item analysis. It is therefore appropriate to retain these findings and present them in relation to the qualitative data in the following chapter, where interesting and clinically relevant points may be raised. In this respect this present analysis serves as an important frame of reference for the qualitative analysis to follow.

i. Previous Experience of Stress

It is noted that control group ii have a slight increase in the number of distressing life events, although not at a level of statistical significance. However, on further analysis, the relationship between age and distressing life events indicates that the under fives have experienced a greater number of stressful events in the preceding year (50%) (table 2, Appendix 3.). This finding is consistent with the concurrent finding of new siblings being born into the families of the pre-school child. The qualitative analysis will address the nature of these distressing life events and discuss their relationship with the child's subsequent coping during in-hospital care.

ii. The Pre-admission Profiles - Attachment and Social Behaviour.

The rationale for the development of items included in these summary scores has been made with reference to the selection of a conceptual analysis drawn from the developmental literature (p. 174). No significant deviations from the norm were noted. The application of random sampling has secured an acceptable match on pre-admission behaviours across the three groups.

iii Family Variables.

The above summary score indicates an acceptable match across the groups of the situational and family variables which influence the parent's response and ability to cope in practical terms, with the events leading up to the hospitalisation of the child. This data may influence the incidence and intensity of parents expressions of anxiety, which is measured by GHQ-1. For this reason, the relationship between parental coping before the child's admission and the parents' subsequent responses will be examined in the illuminating light of the qualitative data.

9:6 OUTCOME MEASURES.

The effect of the experimental intervention will now be addressed. Child coping before admission will be reflected in the summary scores which include the parents perception of the manifest anxiety observed in the child; the child's approach to seeking out hospital-related information and changes observed in the child's behaviour and demeanour prior to coming into the ward (following preparation). The parents' pre-admission coping is indicated by the summary scores derived from the GHQ-12 and represents changes in parental perception of anxiety in the days preceding the admission.

Table 4. Analysis of Outcome Measures - Summary Scores:

i. Child Coping Pre-Ad.	K.W	Chi-Square	Mean	Std. Dev.	P Value
Experimental	42.3		1.11	1.63	
Control i	42.2	2.7	1.03	1.36	NS
Control ii	51.9		1.50	1.45	
ii. Parent Coping Pre-Ad.					
Experimental	47.9		5.50	4.97	
Control i	40.0	1.9	4.06	3.95	NS
Control ii	48.5		5.97	5.62	
iii. Child's In-Hosp. Adjust.					
Experimental	45.9		2.50	.90	
Control i	49.2	1.3	2.56	.72	NS
Control ii	41.3		2.30	.70	
iv. Child's Home Adjust.					
Experimental	40.0		10.46	12.45	
Control i	44.1	3.4	12.20	12.88	NS
Control ii	52.3		16.90	13.52	

Discussion of Outcome Measures.

Again, while no statistical significance is found, some interesting distributions are highlighted across the groups. This is particularly evident in the summary scores which indicate child and parent coping before the child's admission and in the adjustment of the child following transfer home.

i. The Child's Pre-admission Coping.

The above summary relates to the specific aspects of preparation for hospitalisation. This is a report of parental perception of the responses of the child, as recorded on the pre-admission questionnaire, after he/she was told about the forthcoming admission. The low response rate, (63.3%), due mainly to parents forgetting to bring the form with them on the day of admission, limits the value of the above findings, which show an interesting distribution. Control group ii score higher on this summary. It has been stated earlier in this study that while the additional attention given to control group ii was specifically

not related to preparation, the effect of the attention may have stimulated emotion focused coping in the days preceding the event. This may suggest that this group was actively working through the process of coming to terms with the forthcoming events. In addition the parents in this group may have spent more time talking with the child about the forthcoming admission, because of the need to complete the diary on a daily basis. The diary referred to will be reviewed briefly in the final chapter.

ii. Parent Coping Prior to the Child's Admission

Discussion.

The data presented above represents a retrospective account of the parents' adjustment in the few days preceding admission of the child.

It is the explicit intention of the GHQ. to ask only about recent symptoms, the inclusion of 'the same as usual' response is considered by the authors of the manual (Goldstein and Williams, 1986), to be a way of ensuring only recent changes are reported.

The twelve items on the GHQ were analysed and frequency and chi-square statistic computed. The overall finding is of a high level of anxiety across the three groups (figure 4) The experimental group experience a greater *expressed* level of anxiety on some key items, in particular 'feelings of panic'; 'feeling unhappy and depressed'; and generally 'poor coping' in the days preceding the child's admission. The cross-tabulations showing these findings are included in the appendix. There is an apparent though not, statistically significant, difference between the groups, with control group i showing a lower score on the GHQ score.

While the present findings suggest a negative effect of the experimental treatment of the mother's pre-admission coping responses, interpretation of the qualitative data is expected to illuminate this issue.

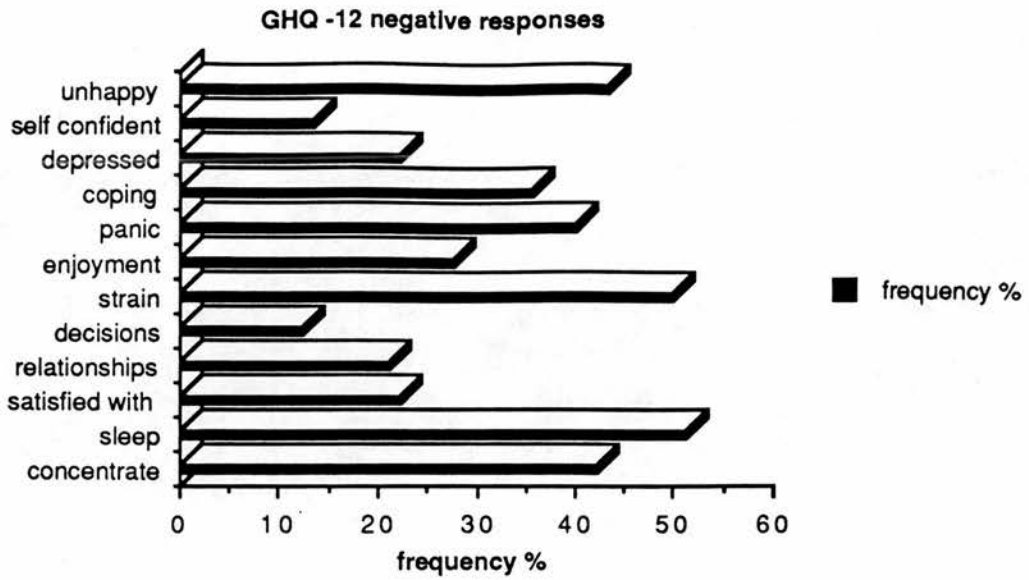


Figure 4. The Incidence of Parental Anxiety - Pre-Admission.

The above graph shows the frequency of negative effects on the 12 variables which represent the GHQ-12. Since only recent changes were asked, a pre-test-post-test comparison was not considered to contribute to an understanding of maternal anxiety before the child's admission and surgery.

Age of the Child and Maternal Anxiety.

The age of the child is identified throughout this study as an important variable to consider when predicting the child response to hospitalisation. Similarly, the age of the child is also considered to influence the parent's level of anxiety as she prepares to admit her child to hospital for surgical treatments (Skipper et al, 1968; Roberts et al 1987; Caty, et al 1989). The relationship between age of the child and maternal anxiety is now presented. Mean and standard deviations are cited for the two age groups studied.

Table 6 Incidence of Maternal Anxiety and age of the child:

Age	3yrs - 5yrs.	5yrs - 7yrs.
Mean	6.413	3.886
Std. Dev.	5.867	3.258

$p = NS$

The above mean table shows an interesting distribution. It may be speculated that the

mothers of younger children perceive their child as less able to rationalise the events in terms of positive health outcomes. Also the conceptions of health and illness held by the younger children are more likely to be in terms of hospital treatments being perceived as punishment for past or imagined misdemeanours (chapter 3). Parental feelings of inadequacy are at their peak when the parent is attempting to relate the reasons for traumatic events to the child who is in the pre-operational stages of cognitive development. This finding supports the empirical evidence from the previous studies, for example, Peterson et al, (1986), Dunn et al, (1980). The former study highlighted the need for parents of pre-school children to be closely involved in the care of their hospitalised child. A further factor is the perceived vulnerability of the younger child. A frequent comment made by parents in relation to how they (the parents) envisaged their child coping during in-hospital care, consistently identified age as being a particularly worrying issue. Verbatim comments will add presence and insight to this area, and will be presented in the next chapter.

The influence of Social Class on Parental Anxiety.

Social class was examined in relation to the twelve items on the GHQ. Individual item analysis signalled the need to address the influence of social class on parental anxiety for example, expressions of parental panic and inability to cope, were more frequently cited in the higher social groups. This finding will be identified and discussed in relation to the qualitative findings.

iii. The Child's In-Hospital Adjustment

The above findings indicate no significance across the groups. However, interesting distributions are apparent. Observation of manifest upset and co-operation show the first control group to be overtly more distressed than the other two groups.

Clinical observation by the nurses responsible for rating child responses, confirms the importance of looking to the effect of maximum stress points during the hospital experience, in relation to subsequent adjustment. These stress points represent for example, separation from mother on the day of operation, transfer to the operating theatre and induction of anaesthesia. Blind observer ratings which formed the basis of the manifest upset and co-operation scores, also include comments appended by the nurses to enlarge upon and further explain an aspect of her observations. This important and illuminating data will be presented in the qualitative discussions.

Individual item analysis identified group and age differences and a level of significance was shown for items representative of maximum stress points, for example, transfer to the operating theatre and induction of anaesthesia. This is an excellent example of the need

to be aware of the possible inter-relationship between statistical significance and clinical importance. This central issue, will be referred to during the integrative discussion which is presented in the next chapter. The tables of interest may be referred to in the appendix.

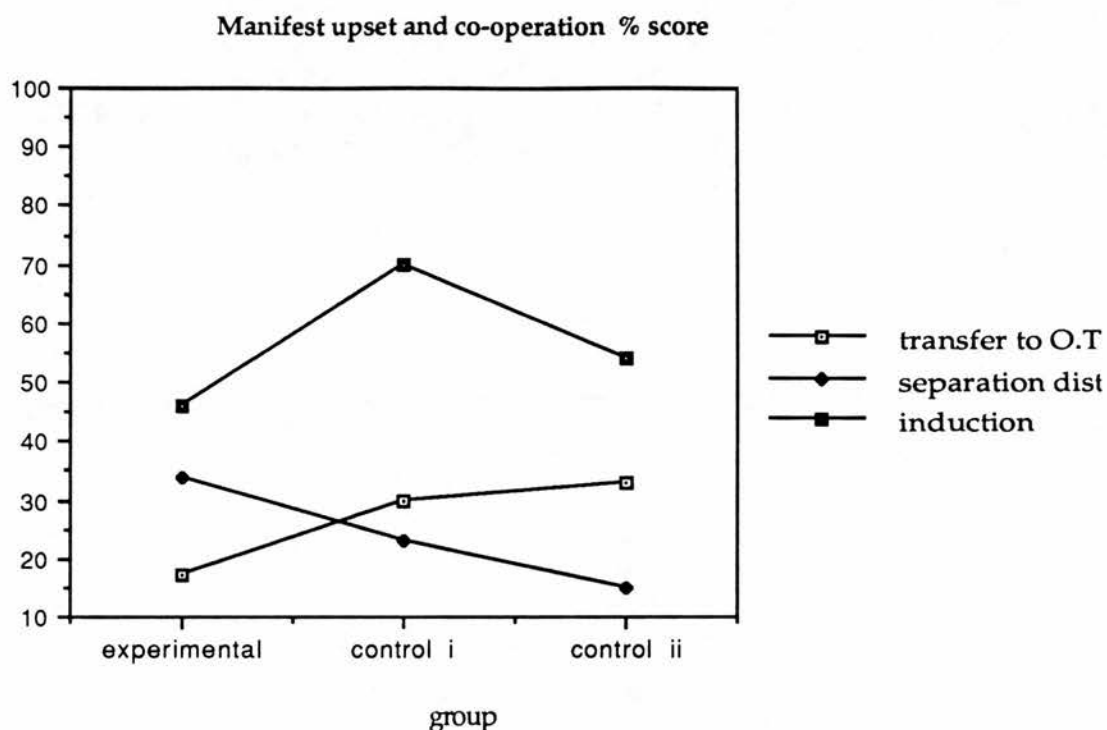


Figure 5. Manifest upset and Co-operation - maximum stress points and group performance.

The above graph which shows the percentage score across the three groups, indicates variable performance in relation to the maximum stress points during treatments. The experimental group appear to cope better with transfer to the operating room and induction of anaesthesia, while coping less well with separation from parent during the experience. The influence of age during the in-hospital treatments failed to show any significant findings. This will be reviewed in the light of parental expectations of their child and will be discussed in a later section.

iv. Home Adjustment

Post Hospital Outcomes, the Post Hospital Behaviour Questionnaire.

Four response categories were available on the post outcome measure, this was collapsed to three categories for the purpose of analysis, following initial frequency runs, where the presence of relatively empty cells were noted. The 'same as before' response was

interpreted as no change in behaviour , while the 'better than' before response indicated an improvement in the variable. The final category indicated a deterioration in behaviour. The PHBQ is of value in addressing the research questions in relation to positive as well as negative change in behaviour. Comparison with parents stated positive changes and changes observed on the PHBQ are of interest. This relationship will be explored during the qualitative analysis.

No significance was found in the experimental group's adjustment to the integration into normal home life following a period of in-hospital care. The distributions suggest that the treatment group had lower scores than control group i (figure 1 and 2, appendix). However the salutary reminder that correlation is not causation is pertinent. This is particularly relevant in view of the inconsistency of performance of all three groups, with the treatment group fairing 'better' on some items while the control groups fared better on others. This individual item analysis is integrated within the qualitative discussion.

Positive Changes in the Child's Post-Hospital Behaviour

This data is not included within a summary score, since it represents only one question specifically asked in relation to positive change. In addition, this question was kept separate from the PHBQ since it was important that the parent respondent saw this as a fresh appraisal of their child's current behaviour and not as part of a continuum of responses. In this way the positive changes reported on the PHBQ may be reaffirmed and described by the parent respondent.

It is frequently observed that parents will respond positively to a perceived change when that change has particular meaning for the parents in the context of the post-hospital recovery of the child. The Post Hospital Behaviour Questionnaire provided the vehicle for parental perceptions of outcomes, both in relation to their own level of satisfaction and in relation to the child's subsequent adjustment.

Positive changes in the child's behaviour post-hospital are reported:

Frequencies:

Positive change reported by parent	28.9%
No change reported	71.1%

The influence of the independent variable was then examined in relation to positive change:

Positive Changes across groups.

There is a significant difference between groups reporting positive behaviour change following admission and surgery, with the additional attention group (control ii) reporting a higher incidence of positive change. The experimental group also report a level of positive change (30%).

While the attention given to control group ii was specifically unrelated to preparation, focus on the individual family may have contributed to the overall sense of well being and perceptions of individual care. As addressed in the methods section, the possibility of enhancing emotion focused coping using this approach to attention control is apparent. The post outcome statements from parents in all three groups, which asks about satisfaction with all aspects of care, including preparation, will further inform this issue and are presented in the next section.

The influence of social class on expectation of change is also reviewed in a later section.

Table 7. Positive Change following transfer home.

<u>Group</u>	<u>Positive changes</u>	<u>No changes</u>
experimental	9 (30%)	21 (70%)
control i	1 (3.3%)	28 (93.3%)
control ii	16 (53.3%)	14 (46.6%)

chi-square-19.666

p 0.0006

The above table shows the changes in behaviour perceived by the parent to be positive, two weeks after the child's transfer home.

Age and Expectation of Change.

There is an apparent though not statistically significant relationship between age and positive change after hospital (appendix table 19). This however requires to be observed alongside the expectations of the parents in relation to age and change expected, since the literature supports the view that parental expectations colour the actual observation of and reporting of change by way of emotional contagion (Campbell, 1967 Eiser, 1985 .

Parent expectation of change and change subsequently observed by the parent is presented in the following chapter, since the qualitative data informs the nature as well as the frequency of parental expectations.

Reporting of *negative* changes was facilitated mainly by way of the PHBQ. Full accounts

of the nature of the changes as perceived by the parent are presented in Chapter 11, since they contribute to an understanding of the experiences of the families in relation to the preparation approach received.

9:7 Summary of the Analysis.

The decision to compile summary scores as an organising concept and for economy of presentation, has necessarily raised questions in relation to the absence of statistical significance on the outcome measures within these summary scores. As indicated throughout this presentation, aggregating scores has the effect of immersing potentially meaningful data within the overall summary. However, having initially analysed the individual items and identified levels of significance within these items, the decision to proceed with summary variables was taken with the assurance that data which could contribute to an understanding of the total experience, would be preserved.

As outlined in an earlier section, consideration of alternative approaches to the analysis of this data was considered. These included the application of factor analysis. This seemed particularly relevant in view of the use of this approach by Vernon (1966) in his original work with the Post-Hospital Behaviour Questionnaire. The limitations of the relatively small sample size in the present study, rendered a factor analysis inappropriate to this data. Similarly, cluster analysis was considered but rejected because of the limitations of this approach when a three sub-sets analysis is required, that is the effect of group assignment on the responses throughout. The pre-test-post-test approach was also considered. This involved looking at the same items on the child's pre-admission profile and effecting a direct comparison with his post-hospital outcomes. This was considered to limit rather than enhance the analysis of this data, since the purpose and content of pre and post data in this study are not the same.

In answering the research questions, the influence of the independent variable that is, the nature of preparation is assessed in relation to group performance on key individual and summary variables.

Random sampling secured an acceptable balance on the key confounding variables, with the exception of gender, which in control group ii resulted in 50% more girls than boys. Identifying crucial variables in a study of child health care is fraught with the risk of focusing too narrowly on specific events which represent only a part of the process of that health care. In the main, this risk is avoided in this study by constant reference to the theoretical underpinnings, which clearly identify stress and coping as a process. In addition, reference to the need to effect an integrative interpretation of the data which

represents combined methodologies, focuses attention on the equal value of, and the inter-relationship between, quantitative and qualitative data.

Notwithstanding the limitations of sample size, the writer also recognises the need to look further at the sensitivity of the instruments used. While validation in other studies has been achieved, many of these studies also failed to show a level of statistical significance for substantially larger groups (Visintainer and Wolfer, 1979, Azarnoff, 1982). The rationale for the use of the instruments in this study, together with the modifications required to address context and sample size have been addressed (chapter 5).

In view of the absence of appropriate tools, the opportunity exists within the clinical area, to further develop the instruments used in this study. There is a need to increase their sensitivity and, in particular to address the developmental issues more closely. For example, the same approach is used for children across an age range. The writer sees much benefit in developing instruments which may tap the differences in developmental stage as well as in other important individual differences, for example, temperament. The main barrier to this approach is generally that of limited resources. It is accepted that time to follow-up children to ask them directly about their hospital experiences is time consuming, particularly when a wide geographical area is represented in the sample. A further challenge is to devise instruments which would reflect the experience of children across the age range studied. This is particularly pertinent in this study as pre-school children alongside school-age children are included. However, if the obstacles of resources were to be overcome, the child as a *respondent* instead of total dependence on parental perceptions, may then become a more viable goal. In this way, the research instruments would address more closely, the marked individual differences amongst children within the age range studied.

Parental Anxiety

It appears that the experimental treatment has no clear benefit in relation to the level of pre-admission anxiety expressed by the parents. The present author speculates that this is because the treatment group appreciated and accepted the reality of the events and were coping with them in their own way; that is ranging from emotion focused coping to problem focused and mastery. The scoring option adopted for the GHQ-12, required adherence to the categories described in the validated studies (Goldberg and Williams, 1988). The small sample size in this study is a limitation when using more than two category responses, particularly, with an additional control group. Further studies would require to look more closely at the scoring options; and sample size would require to increase each group considerably before any definitive statement can be made about the

effect of the experimental treatment on parental anxiety.

Attention to parental reports of satisfaction with the events will provide further data about the efficacy of the experimental intervention and these data are drawn from the qualitative analysis.

In hospital adjustment

This group of variables is representative of maximum stress points during the child's experience of the stressful event as defined in previous studies (Azarnoff, 1984). The distribution suggests that the attention control group coped more adaptively with the overall experience. The experimental group however, were reported as coping more effectively with the identified crucial stressors, as reported on individual item analysis (appendix table12). This is a particularly interesting finding, since induction of anaesthesia consistently emerges as the single most important source of anxiety to the parents (Gough, 1990). The effect of parental anxiety in relation to this variable would therefore appear to have less impact on the children in the experimental group. This raises the question of whether, given the limitations of the emotion contagion hypothesis (chapter, 4), the effect of individual preparation of the child can circumvent the most powerful source of parental anxiety. This important issue will be discussed in the following chapter.

Post Hospital outcomes.

The distributions show interesting findings which may suggest that the treatment group have integrated into home routine and adjusted 'better' than the control groups. Interestingly, the attention control group fared less well than the first control group (see tables in appendix). The parents perceptions of how the child coped with the overall experiences provide illuminating data, which is discussed in the next chapter. As indicated earlier in the present study, the most effective way to find out about a child's responses to hospital and subsequent adjustment, is to ask him. This was not possible in the present study for reasons explained earlier, particularly the logistical problems of following up 90 children scattered throughout a wide geographical area, two weeks after transfer home. Further studies would require to attend to this limitation, which includes also, the need to relate effectively with the varying developmental stages of the children sampled.

Positive behaviour change.

The attention control group show a statistically significant positive change in behaviour two weeks after admission and surgery ($p = 0.0006$.) The treatment group also show a positive change in behaviour after the event, although not at the same level. It is observed (appendix, figure 1) that the attention control group expressed concern about the child's physical recovery after home-coming, as reported on the open responses on the PHBQ. It may be postulated that over-emphasis on physical symptoms influenced the sense of well-being experienced by parents and child when subsequent recovery was made. The response to the question in relation to positive change may therefore have been coloured by the 'relief factor' that all was well. Alternatively, the attention control group may simply have demonstrated more actual positive change in behaviour. It is interesting also to note that the attention control group did not expect change to the same degree as the other groups.

In summary, the statistical analysis suggests that the attention control group and the experimental group coped overall, more adaptively than the standard preparation group. This raises the question, already referred to in the methods chapter, of whether the second control group did in fact emulate the treatment group in that the effect of the additional attention constituted additional preparation. At a practical level this did not seem to be the case, since the nature of attention was specifically unrelated to preparation. Also the time spent with the additional control group was only fractionally more than that spent with the group which received the standard preparation.

The writer is of the view that the effect of the additional attention may have stimulated emotion focused coping in control group ii. Further study would require to address the issue of a second control group, looking specifically at how the parents perceive attention during periods of heightened anxiety. Finally, in making a statement about the efficacy of the experimental intervention, while remaining mindful of the adage that correlation is not causation, it is appropriate to reiterate the 'better' adjustment of the children in the experimental group on the post hospital outcome measures. A logical development of the present study would be to follow the children longitudinally over a longer period of time, with the aim of assessing their response to subsequent medical and social stressors and thus evaluate the longer term effects of the intervention on the experience of a brief encounter with the stress implicit in admission to hospital.

The above findings have answered the main body of the research questions in relation to quantitative data. Given that both methods chosen are equally valued, the quantitative analysis has set the scene for the interpretation of discourse presented in the qualitative

data. This analysis has also raised many questions which require a in-depth analysis of child and parent experiences in relation to the psychological and social milieu within a paediatric surgical unit. For example, the nature of the anxiety experienced by children before they are admitted, in particular, their perceptions of the forthcoming events and the subsequent coping responses made. Also it is important to explore parental perceptions in relation to how the child and the parent subsequently coped with the post-hospital continuing care; a hitherto unexplored area in relation to ear, nose and throat nursing. Post hospital outcome up to two weeks following transfer home are presented and represent the child's adjustment into a normative home environment. The manner of adjustment and the nature of the adaptive responses made by the child are the subject of parental perceptions and are subsequently analysed within an interpretive framework . It is to analysis of the qualitative data that we now turn.

CHAPTER 10

ANALYSIS OF QUALITATIVE DATA. (1)

RESPONSES OF THE CHILDREN.

10:1 Introduction

The data presented in this chapter were harvested from the range of five questionnaires used throughout the course of the data collection. These questionnaires represented specific temporal phases of the process which spanned pre-admission preparation, in-hospital care and post-hospital adjustment of child and parent. The approaches used to present such wide ranging reflections of child and parent experiences require to be specified.

A major challenge was to devise a way to achieve a sense of the whole whilst analysing the parts comprising the whole. Management and organisation of data are an integral part of the analytic and interpretive process adopted in this study. This is particularly important, since the aim is specifically not data reduction and subsequent building up, but rather to come to an ever richer understanding of the parts and then effect an interpretive meaning of the whole.

The pursuit of understanding of the stress experience of child and parent is facilitated by the application of the conceptual foundation upon which this study is based. The stress and coping paradigm (Lazarus and Folkman, 1984), which views stress as a dynamic process, is further explicated by the application of discourse analysis within a hermeneutic phenomenological framework. Hermeneutic interpretation is particularly relevant as I attend to the influence of the responses made by the child and parent at the outset and throughout the encounter and use the understanding gained at one point of the process, to inform and further interpret and subsequently understand the meaning of the total experience to child and parent. The value of the hermeneutic circle of inquiry is apparent in this study as I seek to interpret and understand the meaning of the parts in relation to the whole, and the whole in relation to the parts. The constant interplay between the different levels of analysis is important, as the stress and coping process is seen to be informed by attention to the clockwise and anti-clockwise movement within the circle of enquiry.

In addition, a hermeneutic framework establishes an appropriate conceptual bridge

between the quantitative analysis and the discourse analysis of the present section. Hermeneutic reflection is seen to mediate between the respective languages of statistical data and analytic discourse. In this present analysis, hermeneutic reflection forms a bridge, an epistemic link between the combined method applied to this study. In particular, hermeneutic reflection makes explicit the presuppositions of the approaches used, their form of abstraction and their guiding concept of method. Knowledge of the findings from the quantitative analysis provide a clear frame of reference for this analysis of child and parent discourse. An integrative perspective, that is, the task of pulling together and forming a cohesive picture of the whole is expected to ensue. A validation of the appropriateness of the approaches to analysis used, will be the extent to which these approaches foster understanding of the child and parents' experience during paediatric admission to hospital for elective surgery.

Organisation of the Qualitative Analyses.

The interview transcripts together with the postal questionnaire responses were assembled for each of the ninety respondents. Responses to each of the twenty two open questions which comprise the qualitative data, were then looked at for the entire sample (these responses are derived from each of the five research instruments and are collated in appendix 3). This was followed by an examination of the complete text across groups. The responses of each individual to the total experience which spans the pre, during and post-hospital events were then analysed. This analysis took the form of a preliminary categorisation of the emerging issues; these issues were temporally specific. This is important, since the context within which the responses occurred is a dynamic one which changes as parent and child progress through the stress and coping process. Understanding of the responses at one level is used to feed into the interpretation at other levels. A richer understanding of the whole is thereby possible. Analysis of the qualitative data therefore, follows the same conceptual structure as that of the quantitative data; that is, the process of stress and coping across the total experience addresses the temporally specific nature of the coping process. Similarly, the research questions are addressed in turn, from the outset of the stressful experience; that is the first encounter the family had with the hospital, through to the child's home adjustment two weeks following surgery.

10:2 The Process of Qualitative Analysis

The specific frame of reference, made explicit by the quantitative analysis, was that of identifying aspects of the experience which were perceived by child and parent as stressful, anxiety provoking or upsetting. Some control required to be exercised over the

voluminous quantity of data, since the early frequency of such occurrences were prolific. Recurring themes, which in some instances, mirrored those emerging from the quantitative analysis were detected. Considerable care was exercised during an exhaustive thematic analysis to identify overlapping parts and to respond to the constant interplay between the parts and the whole. As part of this process, colleagues read excerpts from the text and a discussion of the ensuing independent analyses took place. In addition, the early drafts were shown to a small sample of parents (6) whose children had recently fully recovered from elective surgery. The comments from these parents were invaluable and together with the perspective of colleagues, proved to be an essential step in the analytic process of this study. This was particularly helpful in view of the daunting task of forming cohesion of the qualitative data without losing any sense of the meaning of the whole. A number of recurring themes, for example, separation anxiety, parental uncertainty, issues of parental control and competence, involvement in the child's care, children's perception of the experience, and sibling relationships, were further developed, as were central links amongst the themes.

Writing and re-writing the early drafts of this analysis contributed to the interpretation and understanding of the discourse. Identification of a firm 'unit of analysis' or 'meaning unit' (Giorgi, 1985), is necessary during interpretation of texts. While the meaning may be found to transcend the discourse, to go beyond what is said, to interpret meaning (Parker, 1990), these meaning units must be clearly identified and located within the text. A further benefit of colleagues and parents contributing an objective interpretation was therefore to achieve an audit, an independent validation (Benner, 1985).

As discussed in the Method's section of this study quantitative and qualitative research method are equally valued. The unique contributions of each approach have been considered in order to achieve the dynamic balance required of combined methodologies (Mitchell, 1986). In addition, the link between method and assumptions demands simultaneous consideration. Such consideration occurs on several levels by identifying commonalities in assumptions between the two approaches, rather than solely, emphasising contrasts. A further important point in this analysis is the contribution from the researcher. While attempts were made to maintain appropriate rigour, it is acknowledged that the position outlined by Benner, (1985) where the researcher brings self to the interpretation and subsequent understanding of the discourse, shares common ground with this analytic process. While it is important to acknowledge the contribution of 'self' which the researcher brings to the interpretation of the discourse, it is equally important to reiterate that it is the experiences of child and parent that I seek to understand. To reach this nucleus of understanding it is necessary to look for reality behind

the language used.

Discourse is the meaningful articulation of the understandable structure of 'being in the world' (Heidegger, 1962). The adoption of the approach of analytic discourse within a hermeneutic phenomenological tradition embraces the task of qualitative analysis in this study, succinctly; that is, to describe, interpret and understand the human experience portrayed in the events encountered by parents and their children who are admitted to a Sick Children's Hospital to undergo elective surgery. In this way the research questions which ask about the effect of the experimental intervention on the parent's perceptions of the total experience may be answered.

Approach to Qualitative Analysis - An Interpretive Paradigm

An interpretive approach involves a systematic analysis of the whole text, a similar analysis of the parts of the text and a comparison of the two interpretations for conflicts, and to secure an understanding of the whole in relation to the parts, and the parts in relation to the whole. Analysis therefore has a circular form, the parts are read in relation to the whole and through the hermeneutic process new understandings are developed. Tilley (1990), used the metaphor of the circles of growth marked by the rings in the tree to express this process. Conflicting findings where they are present are analysed with the aim of systematic and controlled confrontation.

The process of qualitative analysis began on completion of the data collection. This process has been on-going throughout a twelve month period. The presentation of the findings represents a part of that process.

A structural analysis of the contents of the twenty-two questions was undertaken. Segmentation of the work identified categories, which were then compared and contrasted, following which, a higher level of integration was possible. This integration facilitated interpretation, where the new reference created by an understanding of the whole was then possible. The circular manner of hermeneutic enquiry is apparent in this analysis. Interpretation proceeds in a circular manner with the understanding of parts contributing to the change of perception of the whole. Ricoeur, (1981) describes this hermeneutic circle as a correlation between understanding and explanation in a dynamic dialectical interactional relationship with one another. The need to understand what one is trying to explain is an important discipline at the outset of the interpretive discussion. The goal is to achieve meaning from the text as a preliminary to understanding. These meaning terms will be exposed to discourse analysis with the aim of understanding the nature of the parent's and children's experiences during the course of the child's admission

for surgical treatments. The meaning of these experiences to the individual child and his family form the core of such understanding.

The interpretive paradigm centres on the view that the social world is constructed through interaction mediated by peoples interpretations of the shared intersubjective world (Gadamer, 1976, Harre. 1979, Outhwaite, 1987). The conceptual links between subjectivity, intersubjectivity and the construction of social reality are of central importance. The link is through language. The aim of interpretive analysis is not truth, but rather a richer understanding. Harre (1983) argues:

... the demand for the final absolute unreversible truth cannot be met..., it is not even viable as a theoretical ideal. The possibility of endless re-interpretation must remain and it must be admitted that each interpretation has some explanatory power. (p.78).

The approach applied to discourse analysis in this study has been referred to in chapter 5. Reference will be made to Parker's (1990) different levels of analysis as they relate to the interpretation of this data. All language, even simple description is constructive and of consequence to the discourse analyst. Some cohesion and bringing together of divergent positions is likely to contribute to an insightful interpretation within a large data set. The wealth of data which this study yields is in part indicative of the context of the research and the open and expansive responses of parents as they cope with the anxiety of having a child admitted to hospital. No attempt will therefore be made to present all the data. This is a reflection of the limitation of time and overall length of the write-up, rather than the validity of the responses. Clearly, careful selection and focus on the aspects which particularly enhance the understanding sought, is an important discipline in this study.

It is apparent when working in the health care field that the same phenomenon can be described in a number of different ways. Variations in accounts add to the richness of the phenomena under investigation. Potter and Wetherall (1987), point out that there is no foolproof way to deal with this variation and to sift accounts from those which are "literal and accurate from those which are rhetorical or simply misguided" (p37). This is seen to be an unnecessary distinction in this study, since all parents responses are valued as unique. Analysis of the meaning implicit in the statements are explored with reference to the context of the discourse, perceived needs of the parents, as well as the experience brought to the analysis from outside the discourse by the researcher.

Much of the early work on the first drafts of this analysis probed the conceptual framework of this interpretive chapter. Considerable time and reflection centred on the

necessary conceptual mapping during the early category analysis. Identification of the core theme as that of coping within the context of child-in-hospital, undergoing surgical treatments was consistently teased out from the thematic analysis. In addition, other important themes are seen to contribute either to an understanding of coping in context or to a further dimension in the understanding of child and parent experience. Therefore, while coping may be seen to be the nucleus, streamlining the early drafts of this analysis has led to the identification of additional themes. It was my intention at the outset to avoid imposing a firm and inflexible structure on this analysis, but rather to achieve a logical and organised account in which the data speak. My interpretation of the data presented in this chapter is a culmination of the fruits of this task.

The purpose then of applying discourse analysis to the present study is to interpret and understand the character and intent of language expressed by parents and their children (via the parents), as they progress through the process of stress and coping with the child's surgical treatments. This is facilitated by the conceptual framework which underpins this study (Lazarus and Folkman, 1984) and made explicit by the application of discourse analysis within a hermeneutic framework.

10:3 Structure of the Presentation of Qualitative Data.

The Children.

The sequence follows a similar pattern to that adopted for the presentation of the quantitative data; that is, the pre-admission data is reviewed to further inform the pre-admission profile of the sample. This is particularly important in relation to the perceived impact the event has on the family before admission and the relationship between adjustment during and after the event. The outcome of the event is then analysed in relation to child coping responses.

This analysis follows the child through the, a) pre-admission, b) in-hospital and c) post-hospital adjustment process and addresses the influence of key variables on the observed responses. The findings from the quantitative analysis will be applied to an integrative discussion of the findings.

Reference to the specific focus of the quantitative analysis has been made (section 1) and the opportunity to gain a deeper insight from the qualitative analysis was suggested. It is necessary, as a preliminary to this aim, to look at the qualitative data from a narrow conceptual window in order to gain this overall wider understanding. This will be achieved by looking to individual item analysis in the light of the findings of the summary variables presented in the preceding section, prior to exploring the wider focus

required of this qualitative analysis.

The Parents.

The parents perspective will then be examined in the light of the analysis of child responses. This segregation of parent and child analyses is intended to assist in the clarity of presentation and specifically not to suggest artificial separation of child and parent experiences. The research questions which relate directly to the parental experience of anxiety before the child's admission will be further informed by analysis of the discourse which explores parent coping responses. In addition, the effect of the experimental intervention will be studied in relation to the parents perceptions of satisfaction with the care received before, during and in preparation for child transfer home. The findings from the quantitative analysis will be reviewed and alternative interpretations which lend presence and further insights will be explored.

It is important that this analysis also addresses the close inter-relationship between parent and child experience and the many variables which influence this relationship. Discourse analysis within an interpretive paradigm presents the opportunity to explore these issues.

A note on the use of quotes throughout the analyses.

The information gathered from the pre-admission questionnaires (response rate = 59) is reported as written by the parents, abbreviated only where the response is considered to be repetitive. The data from the admission interviews, recorded at the time of the child's admission, are transcribed and presented verbatim. Time was taken at the end of each interview for the researcher to reflect upon and include, the non-verbal aspects of the communication which would not appear on tape. Where interference on tape reduces the quality of the transcription, responses written by the researcher are then reported. The few occasions when this occurred were due to child or sibling investigating the equipment. This was noted by the researcher and the interview was completed either by writing the responses or by adjusting the location of the tape-recorder. The climate of each interview was specifically set as informal and facilitative, therefore younger siblings were often present and I did not wish parents to feel under any pressure to 'control' their child's behaviour for the purpose of the interview.

It is noted that many parents recorded or discussed more than one response to the same question. This proved to be illuminating, rather than contradictory in the majority. The numbers of differing responses to some questions are therefore higher than the number of respondents who made them.

Individual Case Analysis

Analysis of individual cases is considered to be justified for selected sections of this study in order to examine the effect of the experimental treatment on variables of particular interest. This will be facilitated by the use of the hypersoft package (Dey, 1991), an organisational tool of value in handling qualitative data, prior to proceeding to a second level analysis.

10:4 PRESENTATION OF THE FINDINGS

The Pre-Admission Data.

The History of the Child's Present Illness and Events Preceding Hospitalisation.

This section is concerned with the background to the data collected; that is, a brief history of the reasons for hospitalisation will be given prior to turning attention to the important areas of pre-admission data which may potentially influence the child's responses to hospital.

All children have experienced at least moderate degrees of ear, nose and throat problems prior to being referred for consideration of surgical intervention. Consequently, the children in the sample have, in the preceding year, variously been on antibiotic treatments and have experienced time away from school. This very common presenting history in ear, nose and throat conditions, was confirmed by the case records of the sample. All children have had some contact with their family doctor, usually during acute episodes of tonsillitis or middle ear infection. In addition, all children have been referred to hospital for consultation, prior to the decision to operate. Records from these outpatient consultations suggest that many children were perceived by the parent to be 'unhealthy', 'not thriving', or generally 'below par' as a direct result of the chronic nature of the ear, nose and throat problem. In effect, no children were found to be below weight, height or general nutritional well-being for their chronological age at the point of admission to hospital. However, most children had experienced regular infections and had time off school. These periods away from school ranged from one week out of every three; to one week every few months. In addition, hearing impairment, a problem commonly associated with ear, nose and throat infection, was considered by the consultant

to be of sufficient severity as to influence the child's learning.

A condition of admission and surgery is that all children must be free from infection and other potentially hazardous pre-surgical conditions, for example, unexplained rashes. Therefore, all children have to be well on admission. This is an important consideration, since the child's conception of illness and hospital treatment is generally contingent on tangible evidence of the need for such treatments (Steward and Steward, 1981). The issue relating to parental preparation of the child, which is frequently phrased in terms of 'getting well' or 'going into hospital to be made better', is, not surprisingly, little understood by the child who is well on admission. The child's past memory of the last episode of painful throat infection may well pale into insignificance in relation to the actual present threat of hospital admission. As has been reviewed in chapter 2, appraisal of a stressor involves several simultaneous processes in the child. At a cognitive level, the child must relate current stimuli to the memory of past stressful encounters, define the parameters of the event, and orient the event in time. Thus, the very start of the coping episode is dependent on the child's memory, an aspect highly dependent on developmental level (Duncan, Whitney and Kunan, 1982), and strongly influenced by the level of anxiety and affect (Bartlett and Santrock, 1982).

Memory of past medical events may thus be absent or distorted. For example, Kirster and Patterson (1980), found that many children report that they cannot recall having experienced common physically painful events, for example, a sore throat. It may be that many children have experienced such events, but either do not recall the stressor, or are reluctant to re-experience the event by recalling it. If the child is unable to place the events in any kind of prior experiential context, appraisal becomes exceedingly difficult (Peterson, 1989). This important issue will be a recurring theme throughout the analysis of child initiated preparation. Attention now turns to the important aspects of the pre-admission profile of the sample as they affect the responses to admission and surgery.

Responses to and Nature of Previous Stress.

As discussed in the preceding section, the occurrence, nature and responses to past stressors may positively or negatively influence subsequent responses to stress. (Rutter, 1981-a, Melamed and Seigal, 1980). Of the 19 children across all groups who had experienced a stressful life encounter in the preceding year, 7 children were reported to be outside the normal range of responses as noted on the attachment, autonomy and social behaviour items. Single case analysis was reviewed to further inform this issue. This review showed that the majority of these 7 children (5) had experienced the birth of a sibling, while the remaining two children had lost grandparents. It is noteworthy that one child who lost his father was considered by the mother to be a well adjusted child who was

coping appropriately with the major life stress six months later.

Age of the child appears to be an important variable in relation to the occurrence of events perceived as stressful (appendix-table 2). Mothers perceived 'entrances and exits' to be stressful but along a differing continuum. For example, the birth of a sibling was considered stressful only in so far as the child had difficulty accepting the new baby. Mothers described various coping behaviours ranging from aggression to apparent indifference observed in their child in his attempt to come to terms with the changed situation. Reports of 'clingy' and attention seeking behaviours (for example, loss of autonomy, regression of previously mastered developmental levels), were made by the mothers in this group. Of the two children who had experienced loss, both were considered to be still affected by the loss (9 months and 7 months later respectively).

The children's responses to previous stressors were largely, viewed by the parent to be developmentally appropriate. The major example of stressor, that is the birth of a sibling, has been studied extensively in the child development literature (Dunn, Kendrick, 1980). Responses found in the present sample are consistent with the difficulties experienced by young children in particular, who cope with the arrival of a new baby into the home. The present issue relates to the effect of these past stressors to the present experience. This issue will be addressed in a following section.

Response to Previous Medical Contact.

Parental reports of the child's responses in medical settings showed no clear incidence of upset. This contact was mainly routine visits to the General Practitioner and were perceived in a non-threatening light. Parents commented that the child attended the appointment 'quite happy to go' or 'no fuss at all', usually with the caveat "as long as he/she knew there would be no jags or medicine to take". Some parents (9) commented on the importance of the relationship between the doctor and child in shaping his response to the consultation, for example:

"It all depended on the doctor, he (the child) prefers to see his own, but sometimes we see someone else".

When we discourse analyse a text we require to ask in what ways the discourse is attracting our attention, making us listen.

The above comment is consistent with the child's attempt to find familiarity and the absence of threat in a potentially stressful encounter. In addition, analysis of the texts also indicates that the parents are likely to project onto the forthcoming hospital experience, coping behaviours previously displayed by the child in the above situations, for example:

"He manages the doctors visits well, I'm hoping he will look on this (admission to hospital) as a similar thing".

Conversely, (25) mothers repeatedly expressed uncertainty about how the child would cope with admission. An example of their responses is given:

"He is fine at the surgery, but this is another thing altogether-I don't know how he will cope with all this"

These parents expressed their uncertainty about their child's adjustment to the situation frequently, whether or not the question specifically tapped this area. For example, parents were considered to be expressing their own need for reassurance in two identified areas, that is protecting the child from the threat of unfamiliarity and responding to the perceived expectations of the staff in relation to the child's behaviour as follows;

1. *Protecting the Child from the perceived threat.*

The first is a natural concern for the emotional well-being of the child within an unfamiliar environment during aversive procedures. Frequent reference was made in the parents responses to the anticipation of fear and or confusion likely to be manifest by the child. In effect many parents seemed to be expressing their *own* fears in relation to the specific outcome of the treatments as well as in relation to the child's emotional state. This interpretation is based on the presence of frank anxieties expressed by the parents during later communications. This is discussed in a later section.

2. *Conforming to the behavioural norms of the situation.*

The second area relates to the parents perceptions of the expectations the staff may have of the child in the situation. A few parents appeared concerned that the staff (particularly the nurse) may expect the child to be "well behaved" and any deviation from that expectation may be a reflection on parental competence. Analysis of these texts therefore elicits as much understanding of parental concerns as of those attending the child's coping process.

Analysis of the discourse will now proceed and will follow the child and parent respondent across the course of the experience. Interpretation of text will lead to an understanding of the coping process as it unfolds.

Reponses to Hospitalisation.

Children's Manifest Upset Prior to Admission.

The quantitative analysis (p. 180) failed to demonstrate significant findings in relation to the summary variable which reviewed the immediate pre-admission coping of the sample. However, subsumed within this summary score are individual items which do show a level of significance. Table 3 (appendix) shows the across group distribution of anxiety before admission, $p < 0.031$, the experimental group are perceived by the parent to show less anxiety than the control groups. This finding is interpreted with caution, since, as will be discussed later in this section, interpretation of the nature of the questions asked by the children suggests a much higher incidence of anxiety across both control and to a lesser extent, the experimental group, than the above findings indicates. Certainly it appears that the group who were given more specific preparation, showed less anticipatory anxiety.

How the Anxiety was Manifest.

A return to, or an exaggeration of, attachment behaviour was reported by the majority of the 19 (n=59) parents who observed anxiety in their child. These attachment behaviours were evident across the range of the child's day to day activities. These included: coming into bed with parents, following Mum around the house and a greater dependence on transitional objects. Autonomy and social behaviours were also influenced by the news of the forthcoming hospital admission:- for example, further dependence on the parent for previously mastered tasks, for example, dressing, help with eating, apathy and or hostility during sibling play was also reported as was loss of temper and resistance to parental attempts at reassurance. The re-emergence of temper tantrums was also reported in five children (all over 5 years of age).

Regressive behaviours include predominantly, bed-wetting, and 'playing-up' at meal times. Episodes of aggressive behaviour and disobedience, together with emotional lability was also reported in eight children. Implicit in the above observations made by the parents is the child's fear of hospital perceived as an unfamiliar and threatening environment which may involve separation from parents and loss of autonomy. Separation anxiety is a recurring thread throughout the parental reports of child coping before and during the experience.

The above behaviours are entirely consistent with the process of adjustment required of the child during the process of acceptance of a forthcoming unwelcome event. The exaggeration of normal attachment behaviours may, in context be viewed as coping strategies (Karoly, 1982). The degree of anxiety reported is noteworthy. In addition to emotional

manifestations, expressed concern about the overlap between emotional and physical 'symptoms' also emerged from the analysis of parents' reports. It is relevant to note that more than one observation of upset was reported by the mother for each child.

*"Her eczema started up again, I always know when she is upset about something"
"He has gone back to 'cuddly' (a transitional object) and thumb sucking, we thought we left all that behind last year, but I suppose he needs some comfort to cope with all this." (6 year old boy)*

The interplay between emotional upset and the occurrence of atopic eczema is well documented in paediatric practice (Prugh, 1983). The need for transitional objects is, in many children, a developmental norm. The age at which children can voluntarily abandon these objects varies widely and is dependent on the emotional climate of their ecosystem as much as on their developmental stage. The mother (above) addresses the child's emotional state by accepting his need for comfort. This child is in fact enlisting the help of thumb sucking and his old transitional object as an active coping strategy. Eating problems, a further manifestation of emotional upset was variously interpreted by the parent respondent as attention seeking behaviour, or acute anxiety about the forthcoming admission: (12 occurrences of eating related 'symptoms'- no group differences).

*"This eating business has become a problem, I don't know how you girls will manage to persuade him to eat"
"He is really quite upset to hear about all this, he is a good wee eater, but he is starting to pick at his food, I don't want this to interfere with his eating"*

More pre-school children were reported to display appetite difficulties prior to admission. The relationship between age and manifest anxiety before admission is found to be significant ($p = 0.03$, appendix-table 4).

The mother respondent may also be considered to be seeking confirmation of the attention which will be given to her child's nutritional well-being. In accepting that a major part of control over events will be delegated to the staff, the mother may also be seen to be "asserting her rights, specifying her terms" (Alderson, 1990).

Some children were reported to be generally complaining about non-specific aches and pains (9 occurrences). One mother related this to advice overheard by her child:

"She is all aches and pains, never stops complaining, just anything from a sore throat to a tummy pain. I think she heard the GP say she had to be well before they could do the operation"

The child as an active agent in his/her own coping is exemplified in the above comment. Coping in hospitalised children is reported to span a wide range of approaches and strategies (La Montagne, 1986). Lindsay and Powell (1989), make reference to the child under threat as "manipulating every avenue of escape in a cognitively active and at times creative manner". A major assumption underlying this cognitively oriented approach is that coping can be influenced and, in large part, determined by personal and situational factors specific to the individual. Interpretation of the responses of children to hospitalisation will further the understanding of the coping approaches applied throughout the experience. In psychoanalytic terms, the child is displaying a normal adaptive response to an unfamiliar event. Separation anxiety emerged as an important concern to some children .

Perceived Uncertainty, manifest as Separation Anxiety .

Further comments reinforce the degree of separation anxiety observed by the parent: (eighteen occurrences along a similar dimension)

"He/she is much more clingy and won't let me out of sight"

"He/she is very weepy and is behaving badly"

"I need all my patience, he is being really contrary and difficult"

The above comments represent a healthy protest to an unwelcome situation. The child may be seen to be lodging his protest at his level of cognitive maturity. Psychosomatic implications are seen to be an added dimension and one which can pose a source of further anxiety to the parent. Conversely, an interesting finding relates to parents reports of overly compliant behaviours. This is seen by the parent to be an indication of anxiety, for example:

"...He/she has been so good, helpful and doing what she is told"

Some parents went on to interpret this behaviour:

"...I think she thinks that if she is so good we will be able to say let's forget the whole thing"

Summary of Parent's Observations of Children's Pre-Admission Manifest Anxiety.

While analysis of the quantitative data show no significance across groups and age range, individual item analysis, while necessarily initially narrowing the focus, contributes to a greater understanding of the upset shown by children before they are admitted to hospital. Appraisal of a stressor involves several simultaneous process in the child. At a cognitive level, the children above are seen to be actively negotiating the stressful stimuli and indicating their dependence on maternal presence as a coping strategy. The children above, are having some difficulty defining the parameters of the stressful event, for example, its intensity and duration. The importance of reference to past experience with stress is apparent as we interpret the above coping responses made to the news of the impending event. The very beginning of a coping episode is dependent on the child's memory, an aspect highly dependent on developmental level and strongly influenced by the level of anxiety and affect. The difficulty experienced by the child as he tries to place the event into some kind of prior experienced context is apparent in some of the behaviours displayed by the children, for example, psychosomatic 'symptoms', in which the child is signalling his distress and need for reassurance.

Control group ii are notably more distressed by the anticipation of the events than the other two groups (appendix-table 3). The effect of the experimental intervention appears to be of some importance in mitigating some distress, prior to admission. A caveat is offered in that attention to the interaction of the range of variables requires to be addressed before any substantive statement can be made. This is presented during this and the following sections.

It is evident that children are capable of very creative attempts at managing stress. Chapter 3 discussed the developmental issues in relation to children's conceptions of illness and medical treatments. It is suggested that the children (above) are invoking the bargaining counter, attempting to negotiate around the situation in which they are striving to retain some degree of control. Alternatively, the children may be making amends for imagined misdeeds as they perceive admission to hospital as a form of imminent justice (Piaget, 1932).

The verbatim comments provide an example of the ways in which parents perceived their child's anxiety to be manifest. It is clear that anxiety was present. Reference to the developmental literature suggests that some children were coping in a developmentally appropriate way, while others were attempting manipulation of the situation to achieve their goals, that is a reprieve from the stressful encounter or confirmation of parental concern for their fate within that encounter.

While reference to the quantitative findings present an angle from which children's pre-hospital anxiety may be viewed, the qualitative findings paint a broader canvas. The

real extent of pre-admission anxiety can only be appreciated by an analysis of the discourse relating to the nature of the questions asked by the children. These questions reflect the child's conceptions of hospital, treatments and the staff who operate within them, as well as the perceived reason for his admission. An interpretive analysis will therefore be presented.

Questions the Children asked. (reported by the Parent)

The questions asked by the children are interpreted to signal uncertainty, fear and at times frank anxiety in relation to specific aspects of the forthcoming experience. These responses in turn mobilise a wide array of coping approaches. Fifty (n=59) children were reported to ask questions or make statements about the forthcoming events (some mothers listed up to five areas of concern raised by their child.)

There are many identified discrete and intense stressors involved in the child's experience of admission to hospital for surgery. The nature of the questions asked by the children, or comments made by them in relation to the events, highlights some important concerns.

Key themes emerging from analysis of the questions children asked or statements they made, include attempts made by the child to assimilate the experience into his existing cognitive schema. This was apparent in the child's attempts to familiarise the events and the people, and the child's readiness to explore the unknown and express his fears. Various coping strategies were suggested by the children's questions, some actively seeking to acquire new information and thus facilitate re-appraisal based on this new knowledge. Other children invoked an avoidant coping approach. All questions asked are considered to be useful in addressing in the child's unique way, the meaning of the forthcoming event **as he perceives it at that time**. A discussion of the emerging themes, many of which explicate the coping strategy adopted by the child is now presented.

Locating the Events - Coping based on Information Seeking.

"...Will it be like Children's Ward?" (Children's T.V. programme -ITV - Summer, 1990)

"...and will the nurses be nice, what do they (the nurses) do to you?"

In addition to the absence of mature cognitive skills that could aid in the appraisal of a stressor, young children may be more subject to cognitive distortions that will, in turn influence appraisal.

Issues relating to loss of control and autonomy, the fear of pain and the novelty of the situation were recurring themes: (35 occurrences)

"What are they going to do to me, will you (Mummy) stay with me all the time?"

The above comment reflects the child's expressed need for security of attachment in the presence of an ill perceived threat. The child may also be seen to be exploring the unknown and expressing his fears in a more specific way:

"...Will it be very sore, will I get a jag?"

Fear of injections during medical and dental treatments are not confined to the paediatric population. Several studies in the adult coping literature, identify treatments perceived to be painful as being a key cause of pre-admission anxiety (Cohen and Lazarus, 1983 Johnston and Wallace, 1990). Investigations in dental settings have concentrated on injections as a principal cause of fear and anxiety (McTigue and Pinkham, 1978). The children who specified fear of injections as a pre-admission anxiety were all (15) reported to be variously :- 'sometimes upset' or 'always upset' by routine dental examinations, none had experienced dental treatments, apart from fissure sealing, which is not accompanied by invasive methods.

Other questions relating to the nature of the procedures during hospitalisation and the child's role during them are also reported:

The Bravado Approach - Confronting the Anticipated Stress.

On a general level, many children wanted factual information about what would happen in hospital. Specific questions were asked, (mainly by boys) in relation to the detail of the techniques involved, for example: (12 occurrences).

"...How do they get your tonsils out, who does it, is it the doctor we saw when we came here?"

similarly, more graphic descriptions were sought:

"Do they (the ENT surgeons) have to cut your throat to get at your tonsils and adenoids"

Or, focus on the personnel conducting the procedure was also reported:

"Who will take the sore throat away, will the nurses do it when you are sleeping?"

Some boys also expressed an interest in the anaesthetic techniques used, for example:

"How do they put you to sleep, how can they give you the mask and get at your tonsils at the same time?" (boy, aged 6 years, group 2)

The children (above) are cognitively active in their attempts to master the situation; one boy was seen to problem solve in a mature way as he strives to make sense of the technical nature of the procedures. It may also be postulated that such an active and specific focus serves to aid coping by diverting attention from the overall experience. The children are addressing the issues which either represent a particular interest, or are in fact drawing attention to the most fearful part of the process in a plea for reassurance. The 6 year old boy who has clearly thought through the technicalities of the surgical procedure is displaying an impressive level of problem solving, in so doing is coping actively with the reality of the procedure. This apparent level of detachment serves to mask the concerns of the child who may be frightened and confused by the complexity of the events. The level of misconceptions of bodily parts and functions is in keeping with the conceptions explored by Bibace and Walsh (1979) and by Eiser (1985), who report varying levels of misconceptions about hospital procedures. This raises an important issue. The children above were able to express their misapprehensions and were therefore more likely to receive subsequent preparation based on the reality of the events. The children who did not express their conceptions of treatments may be more seriously at risk from immature imagining in the absence of effective adult support. A caveat is noted however. It is frequently stated to be an unrealistic goal for professionals to expect parents to identify and subsequently correct their child's misconceptions of hospital. Indeed, Eiser, (1987) found that adults themselves share these misconceptions, expressed at a higher level of articulation.

Coping with Unfamiliarity - Perceptions of the Environment

Questions relating to the environment were asked by both sexes across both age groups and in all three groups (46 occurrences). The fear of the dark was an important issue raised by the pre-school children, this was frequently linked also to separation anxiety, the following comments present a sample of the issues raised:

"...and are the lights left on in hospital at night"

"Can you (Mum) stay when the nurses go home, so I can have a drink in the night"

Clearly, some children had no perception of the nurse as a constant presence throughout the twenty four hour day. This higher level conceptualisation, that is of the ability to understand the manner in which the hospital as a caring institution operates when providing what the child often considers to be substitute care, is not expected in the younger child at the pre-operational stage of cognitive development. Appreciation of the time span of care has to be firmly grounded in known events and follow a familiar sequence, for example, 'after you have had your mouth wash, the nurses will settle you for the night' 'when you wake up, before you have breakfast, Mummy will be here'. The importance of absolute truth in these predictions is, of course paramount. This issue will be addressed in relation to manifest upset and co-operation during aversive procedures in a later section.

Single case analysis was undertaken to facilitate understanding of the variables which influence the nature of the childrens' questions relating to the hospital environment. Some interesting findings were noted which enhance the understanding of some questions asked. For example, children who had recently experienced the birth of a sibling were noted to relate most questions to the concrete reality of maternal presence, for example:

"...Can you ask the doctor if you can stay, just in case you miss the last bus home and Dad has to feed the baby "

"Is it a big ward - and how will you find me if they (the nurses) move the beds around "

"Why can't you just stay Mum, Jo (the baby) can sleep at the bottom of my bed and you can sleep on the chair beside us"

The very real fear expressed by children about the physical size of the ward and their location in it is noteworthy. The rationale for this fear is based partly on the child's limited appreciation of time and space as a function of his cognitive development. Also, the only contact the child has had with the hospital is during the clinic consultation at the point of referral some months earlier. The child's sense of bewilderment is arguably exaggerated as a result of this limited contact with the bustle and unfamiliarity of the organisation. Consequently, the questions asked are likely to be based on the immature imaginings fuelled by the inadequacies of this brief and unsupported contact. Fear of the unfamiliar is a recurring theme across all groups. As explored later in this section, one benefit of the experimental intervention is the advantage gained by this group of pre-admission contact with the unfamiliar environment and the opportunity to engage in

cognitive rehearsal.

Symbolic Literalism - A n emerging Coping Strategy.

Attempts to earmark his or her own space in the ward, reflects the child's need for continuity of identity and a degree of autonomy. This was suggested by interpretation of the questions relating to the practicalities of accommodation within the ward for example: (19 occurrences)

"Will I have my own bed, can I put my name on it".

"Can I bring my own 'jamies' and turtle games".

"I am not wearing their clothes, I am bringing my own"

"I don't want a bed with bars on I want one like my own"

The symbolic significance of the removal of personal clothing, that is fear of the loss of identity is also reflected in the above comments. Beuf (1979), describes how children react quickly and with great excitement to the dehumanisation rituals which are associated with hospitalisation. A more insightful approach is expected two decades on, which , in the main is implemented in primary nursing within Sick Children's Hospitals. Nurses are aware of the need to avoid the discontinuity which is implicit in the removal of a child from his familiar and secure home environment, to the unfamiliar and often bewildering array of experiences which he encounters on admission to hospital. Children are seen to locate a symbol, that is, in its way a crystallisation of the emotions and ideas they want to express. When symbols are interpreted with reference to the child's developmental stage, the potential to use such communication as a route to interpretation of the child's feelings and anxieties about stressful events, exists. The above responses also suggest that the child is striving to retain ready access to the outside world and to continue to feel a part of it. This is consistent with the discontinuity theory propounded by Hall and Stacey (1979) to explain children's responses to hospitalisation.

The fear of separation from the familiar people, events and the environment of home is more pronounced during the maximum stress points, for example, night-time settling (expressed as fear of the dark) and following surgery (recovery anxiety, fear of pain and separation). This is discussed in a later section.

Children's Perceptions of Hospital

Imminent Justice - A Rationale for Hospitalisation.

Perception of the events as punishment for past misdemeanours was suggested by the comments from 16 children (it is noted that more than one comment was reportedly made by

some children). This finding is consistent with previous work in the field of children's conceptions of health and medical treatments (Bibace and Walsh, 1981). Kirsten and Patterson (1980) identify pre-operational children as more likely to perceive hospital and its attendant treatments as punishment for past misdeeds. Given that children's concepts of illness causality and of the intent of medical procedures becomes increasingly objective and complex with age, (Perrin and Gerrity, 1981) the responses of the pre-school and the 5-7 year old group is considered.

The following comments represent the responses made by children prior to admission: (22 occurrences).

"Why do I have to go away, I don't want to go, I promise I'll be a good girl "

"I'm not going to hospital, I won't go, I don't need to go".

"Please don't make me go Mummy, I promise I'll behave from now on".

Other, more desperate attempts to avoid the situation are noted:

"You can't make me go, I'm going to tell my teacher, you can't send me away".

As predicted by the empirical studies, pre-school children were found to articulate their resistance to hospital admission in terms of perception of the event as punishment. 16 of the sample were in this category, while the remaining 6 children were between 5 and 6 years of age. An interesting sub-analysis showed the six year old boy who had recently lost his father reacting to the event with **apparent** maturity and with a sense of responsibility which belies his developmental stage.

"I think I should stay here with you and Janie (younger sister), how will you manage without me"

Interpretation of this little boys' statement leads to the understanding of his desire to be perceived as in control and coping with the situation. However, it may also suggest a need to be reassured that he *will return home* and that his family will miss him. In addition, a more pervasive interpretation may be that this six-year old is saying 'please don't make me go, I will be helpful and good'. Studies on children of bereaved families suggest a dynamic shift in the psychosocial structure of the family following the loss of a parent (Rutter, 1981-a, Thompson, 1986). Age and gender are factors which influence the subsequent coping outcomes, as well as the presence of extended family support and the pre-crisis relationships within the family (Wallerstein and Kelly 1980). This child will be followed through the experience. Single case analysis is considered justified in the context

of coping with the stress of hospitalisation and surgery when recent family history has had such a profound impact.

Hospitals are where Sick People go .

A further interesting finding arising from the analysis of the questions asked or comments made by the child before admission, relates to the issue of the child's perception of the reasons for hospitalisation and identifies the child's understanding of his or her well-being. Many children pointed out quite factually that they were not ill and only ill children went to hospital. This response may be interpreted as mature attempts by the child to rationalise the forthcoming events in terms of his existing cognitive schema. The child is seen to be actively coping in his attempts to find a rationale for the forthcoming admission, for example: (17 occurrences)

"I am not ill I don't need to go to hospital"

"My sore throats are better now I don't need any operations"

"What do I have to go to hospital for Mummy, I am not sick"

The effects of ear nose and throat procedures are confounded by the reality of the children's statements. They arrive at the hospital pain free and well. They leave three days later suffering acute discomfort due to the effects of adenotonsillectomy, and often a 'flu' like feeling due to the after effects of anaesthesia. It is therefore viewed as a particularly difficult procedure for children to interpret a meaning for and from. This aspect of elective surgery has, surprisingly not been addressed as a key confounding variable. It is suggested that children who undergo treatments for tangible complaints which they can identify as a problem may be able to accept the process of intervention more adaptively (Kirster et al, 1980). It is therefore not surprising that some reports cite negative behaviour change in a majority in the immediate post-operative period (Davenport et al, 1979; McGlowry, 1988; Pruitt and Elliot, 1990).

Actively Exploring the Child Patient Role .

The role of the child during medical treatments is explored in some questions asked by both boys and girls in the sample. The questions were asked by both age ranges and across all groups.

The questions asked generally reflect the need for the child to find security and a degree of identity in the unfamiliar situation and are seen to confirm the interpretations explored above in relation to the use of symbols as coping strategies under aversive conditions. In addition, the questions indicate a healthy curiosity on the part of the children. The circle

of enquiry is seen to move clockwise and anti-clockwise as insights gained lead to a higher level of abstraction during analysis of later discourse.

Some examples of the questions /statements add presence to this theme:

"What do I have to do in the hospital, do I have to do my reading"

"Will I be allowed to get out of bed and play, will the nurse let me watch television"

"Do I have to eat (their food), you (Mum) can bring me in burgers and chips"

(29 references to eating in hospital, 15 of which are negatively phrased.)

Further comments combine the child's need for autonomy as well as clarification of his role in relation to the admission and treatments:

"You (Mother) must tell them that I don't like other people dressing me, I can do it all by myself"

"Can I really keep my own clothes and run around and play with the other children"

"The Nurses can't make me take medicine, tell them I don't need it Mummy"

"Do I have to take my school books to hospital with me"

The patient role as defined by Parsons (1964) sheds some light on the expectations of the child within this role, although Parsons specifically referred to the adult within an institution. The major area of conflict in applying this model to children's responses, is that the adult protagonist has some degree of choice, particularly in relation to elective procedures such as those the children in this study, undergo when taking on the patient role. The child undergoing elective surgery has the role imposed on him.

This issue of proxy consent emerges as a significant one in relation to parental adjustment and will be discussed in relation to the parents' responses (chapter 11). Exemption from blame for the complaint is a condition of the child patient role. This is clearly of importance in relation to the conceptions of illness and medical treatments referred to above. The exemption from other roles, suggests that the 'sick' role eclipses other roles and may offer the child a reprieve from the fulfilment of his other roles; that is the role of a son or daughter and that of a school-child.

The requirements of the filial role remain and are intensified by two conditions characteristically found in the paediatric ward. The first is the tendency of staff to use

the parents as mediators in the fulfilment of medical and nursing treatments: for example, the administration of medicines, compliance with restrictions on activity. This commonly encountered conflict imposes further strain on the mother of the hospitalised child. In addition, the child, rather than viewing the mother as an ally in his time of heightened vulnerability, perceives her as part of the 'opposition', and may feel betrayed by mothers' involvement in the procedures. Indeed many mothers are seen to distance themselves from involvement in nursing procedures, particularly those which are traumatic to the child and parent. On a few occasions, mothers have been observed to stay away from the ward at specific times to avoid the risk of such involvement (personal observation).

The second requirement is that of conforming to the parents perceived image of what the staff expect of the child, obedience and discipline are implicit in this requirement. In addition, the affective demands of the filial role are frequently exaggerated during the child's hospital treatment. Although in the main a reciprocal process, it is observed that parents seem to need the affection and gratitude of the child as a means of allaying their own emotional distress. Beuf, (1979) describes the example of the 'breathless disheveled parent rushing into the children's ward presenting a gift to the child, while complaining about the difficulty of getting there. The child is expected in this situation, to express delight at the parents arrival as well as concern for the inconveniences he or she has experienced in getting there. The gift should be received with appropriate pleasure and gratitude. It is not an uncommon sight, observed by me, to see the child sitting up in bed consolingly patting or hugging his parent. Whether a situation of role exaggeration or of role reversal, this situation does represent *a role* outside the normal child-patient role that taps the emotional energies of the child.

The child is also expected to co-operate in the therapeutic process and to try and get well. As discussed in an earlier section, while many of the demands on the child have a rationale in the manifest function of the hospital, that is the care and treatment of sick children, the demands which arise out of the inherent function of the hospital, as well as the need to function as a safe efficient and cost contained health care provider, can on occasions appear to place the 'needs' of the institution above those of the child as an individual. This is evident in the adherence to the rigidity of routine and practices as perceived by many parents (discussed in a later section), which is interpreted by the staff, in the main, as a necessary function of the smooth, efficient, and safe running of the ward. It is apparent that the child has no instinctive appreciation of the child-patient role. This process involves one of training prior to and during the process of hospitalisation. In the light of the questions asked in this section by children about to enter hospital, one could deduce that a great deal of preparation is required by the majority of the sample.

Much of what passes for socialisation to the patient role at best only prepares the child for isolated aspects of what is a multifaceted role and at worst is inappropriate, communicating an entirely false notion to the child (Strachan, 1988). The literature review explored the role of preparation of well children for possible hospitalisation, given the caveat that such preparation is controlled, well structured and given by informed personnel, the value of pre-admission preparation for non-hospitalised children is worthy of a reappraisal.

Locating the Events in Time

The duration of the total events was also reportedly asked as a direct question by a 34 of the sample.

"How long will I be in"

"Do I have to stay all night - I will miss my Brownies"

"When will I go home, do I have to stay, I could come back another time"

"Will I be home before the next Blue Peter " (favourite TV programme)

"So - I'm to go in one day and I will come out the next"

The above comments identify the need for the child to locate the events in time. Again the use of symbols is identified as the child attaches a familiar event (for example the next 'Brownie' meeting) as representative of the duration of the experience. The above apparently factual questions may also be an extension of the child's attempts to find a concrete reality in the unknown. It is evident that the child's questions imply a need for reassurance that their stay will be minimal. However, an additional interpretation may be the child's reference to a secure base (home) and the knowledge that he *will be* coming home. This is congruent with the work of investigators in the field of children's conceptions of health and illness, that is, the conception of events as a function of developmental maturity and the conception of fear of the unfamiliar as representing pain, mutilation and fear of permanent separation from loved ones (Bibace and Walsh, 1980, Steward, 1981)

An important finding throughout the analysis of the nature and content of pre-admission questions asked by the children, is the expressed or implicit need for continued maternal/paternal presence. Many mothers reported that their child's acceptance of the events was contingent on "Mum coming too". This was a finding across both age groups.

"I don't want nurse to wash me or help me with my teeth"

The child is effectively saying that, if he has to go at all, Mother should be with him and

may be seeking reassurance that she will be. This may be an additional attempt by the child at negotiating his terms of compliance. Involving Mother in practical tasks which may be interpreted as a rationale for her continued presence was reported in 17 responses:

"I will only go if you promise to stay , and help me with my wash"

"I will go to hospital if my baby sister comes too, so you can read to me at night"

While the child's affinity for his baby sister may be an attractive interpretation of the above statement, the knowledge also, that mother is unable to stay away from home for longer periods without her (breast fed) baby may be a more insightful understanding of this six-year old's comment. In addition, the focus on mothers' involvement at night is significant in that this child is expressing her need for mother to be there during the time of heightened need. It is also important to address the possibility that the mother is also using the vehicle of the child's responses, to express her own desire to be involved at the outset.

Summary of the nature of the questions asked.

In summary, the questions asked represent a range of childhood anxieties and misconceptions when faced with the unfamiliarity of hospital admission. They suggest coping strategies adopted by the children. Maternal presence is perceived as an important supportive link with the secure base of home and family. Children also attempt to normalise the events and people connected with the experience. This helps the child to assimilate the experience within his existing cognitive schema and represents a key coping strategy. Coping with the unfamiliar by searching for known 'labels' which the child can identify with a known past experience is clearly documented in some of the responses made. The confusion expressed by some children as they search for a meaning of the forthcoming events is indicative of the health care beliefs held by children and fostered by societal norms. That is;

'Hospital is where sick people go, - I am not sick, - I am not going'. (5 1/2 year old girl)

This indisputable logic renders the subsequent events particularly difficult to rationalise. In addition, if the child is unable to conceptualise hospital treatment in terms of a necessary and beneficial event, interpretation of the process as a punishment for past misdemeanours is the likely outcome.

Children who seek out information and actively ask questions in relation to the event are directly confronting the stress. The relationship between active coping in the pre-admission period and the child's subsequent responses will be looked at in relation to the

manner of coping with manifest upset during in-patient care and subsequent home adjustment. Similarly, the behaviours of children identified as coping along an avoidant dimension will be interpreted in the light of this coping strategy.

The relationship between cognition and emotion was apparent as some children directly addressed the nature of the stress while expressing their emotional response to it. Lazarus (1982) views cognitive activity as a necessary and sufficient condition of emotion. The position outlined by Zajonc (1984) is particularly salient in effecting an understanding of the questions asked by the children:

"In nearly all cases...feeling is not free of thought, nor is thought free of feeling"

(p.86).

The above statement emphasises the importance of an interpretive framework for analysis of child and parent responses. The relationship between emotion and thought is apparent. Emotion is never totally independent of cognition. Some of the responses made by the children may be instant and non-reflective, indicating the personal meaning the event holds for the child at the time.

Implicit also in some children's responses was the need to confirm a positive outcome and be reassured of family support and love during and after the event. This was also related to the child's conception of the events as punishment and supports the findings from other empirical work (for example, Eiser, 1985). All children who asked questions or made statements about the forthcoming admission are perceived to be coping with the events in their unique way. This coping is manifest in diverse and variously effective ways. An important point raised by this analysis is that the children who did address the impending event in **any way** were more likely to receive correction of misapprehensions or exaggerated fears (by the parent). The possibility of reappraisal of the stressful encounter was therefore presented to this group. Although it is pertinent to recall the limitations of some parents motivation and readiness to prepare their child in an effective way. The small group (9) who did not question or otherwise challenge the upcoming event were less likely to have been exposed to this reappraisal. However, it is important to note that cognitive appraisal does not necessarily imply *awareness* of the factors in any encounter on which it rests.

Change in Behaviour Before Admission

When asked if the parent noticed any change in their child's behaviour after she/he knew about hospital (Qu. 4), the following responses which crystallise the meanings which evolved from the child's questions asked and anxiety shown are reported (10 occurrences). It is noted that while 19 children were reported to be anxious prior to admission, 10 were

reported to show change in behaviour at this time. Again mothers recorded several aspects of the same child's behaviour as being representative of showing upset.

The similarity of themes arising affords a higher level of integration as attention is highlighted towards the overlapping of themes across questions.

The statements in a discourse can be grouped together and given a degree of coherence insofar as they relate to the same topic under discussion. Parker's view of discourse is particularly salient:

... discourses embed, entail and presuppose other discourses to the extent that the contradictions within a discourse open up questions about what other discourses are at work. (Parker, 1990, p. 192)

We need to understand the inter-relationship between different discourses in analysis. The adoption of the hermeneutic framework facilitates an understanding of the "ways of perceiving and articulating relationships within a discourse" (Banton and Clifford, 1985). Many of the behaviours identified by the mother respondents reflect active attempts by the child to manage a stressful situation. In contrast, behaviours demonstrating protest against the situation, or those which suggest that the child was having difficulty handling the events, tend to be viewed as failure to cope, or unhelpful to the child. It is possible that behaviours that were non-compliant suggest to the mother that her child was not adapting and was 'coping poorly'.

Examples of the behaviour observed and reported by the mothers are now presented :

"She seemed very angry and wanted to hit out at me, we tried to explain it was for her own good but she seems too upset to take it in" (girl aged 6 years, control i)
"... "It's not fair, why do you have to make me go, I don't want my tonsils out" (boy, aged 6 yrs 6 mths control ii).

The feeling of frustration and anger are implicit in the above comments. and this is consistent with the child being unable to conceptualise a tangible reason for hospitalisation. The 'logical' reasoning which leads a symptom free child to conclude that he does not need surgery, contributes to the feeling of injustice felt when parental choices are in conflict with the child's conception of health and illness.

Parents again reported excesses of affectionate, co-operative and considerate behaviours which they considered to be uncharacteristic:

"He has been a model child this week, very obedient and trying to be helpful.

(boy, aged 6 years. experimental group").

"He has become very affectionate, wanting to sit on my knee and have cuddles, I am making the most of it" (boy, aged 5 years, experimental group).

Parents Reports of change in child's behaviour Pre-Admission:

"He is being quite difficult, not eating or doing what he is told...I think he is really worried about it all..." (boy, aged 6 years, control ii)

"She is very contrary, trying my patience... you try to be very patient at this time, but I think I will be glad when it is all behind us.." (girl, aged 4 years experimental group)

"He is a bit weepy at the slightest thing, we have to watch what we say" (boy, aged 5 years (control group ii)

"He is really very worried about getting jags,... you know, they try to be tough, but he really is just a little boy" (boy, aged 5 years, control group i)

"She has started her eating problems again...she just sucks her food and refuses to swallow. I think you girls are going to have a hard time making her eat after the operation" (girl, aged 6 years control group ii)

The above comments are indicative of the emotional trauma some children are experiencing in coming to terms with the imposed event. Emotional lability signals the confusion felt by children when they are unable to understand the meaning of events. It is also apparent, that the mother is drawing attention to the vulnerability of the child (...*"he is just a little boy"*...), The mother may also be trying to highlight the child's needs in the expectation that these needs will be individually met by the nurses, in this context the mother is seeking reassurance of the presence of an individual approach to care.

Physical 'symptoms ' which may indicate psychological anxiety were also reported:

"She refused to go to school, if it wasn't tummy pain or a headache, she was just feeling unwell" (girl, aged 5 years, control group i)

The above physical manifestations of anxiety may mask the real cause of the child's concern, that is separation anxiety, a need to maintain the security of physical proximity at a time of heightened stress. Most developmental theorists would consider a five year old to be capable of coping with parental absence under normal circumstances. Preparation for hospital admission does not represent this 'normal' circumstance.

"His eczema broke out during the week, I think it's anxiety really" (boy, aged 5 1/2 experimental group)

"He has started a lot of complaints - well, aches and pains really. I took him to the doctors, he seemed to think it was a touch of anxiety" (boy aged 4 years, control group ii)

"He has tried everything, from temper tantrums to faking illness, I think this sore tummy and aching legs will be alright after all this is over" (boy, aged 6 years, control group i)

It is apparent that some mothers do relate physical symptoms to emotional anxiety. The child is seen to project his feelings of inadequacy onto more concrete tangible physical complaints, possibly in a bid for empathetic understanding and a greater appreciation of his present vulnerability . As a coping strategy, it has limited value, since the perceptions of parents indicate that although they realised it was a manifestation of anxiety, few parents viewed their child's symptoms as a plea for help to cope with the threat of the forthcoming event.

All ten children demonstrated an exaggeration of normal attachment behaviour, a frequent comment was the presence of 'clingy' behaviours or other regressive behaviour.

Regressive Behaviours. - coping with the fear of the unknown.

"She is afraid of the dark now and won't sleep in her own room, she hasn't done this since she was a toddler" (girl, aged 3 yrs 6 mths. control group ii)

"She won't let me out of her sight, ...much more clingy since she knew" (girl, aged 4 yrs. experimental group)

"She is coming into our bed much more than before, she won't play with her little sister, just follows me around everywhere, I wonder if it was wise to tell her"

(girl, aged 5 years control group ii)

"He keeps asking...do we have to go now, he is much more attention seeking than before" (boy aged 3 years, experimental group)

"We are back to bed-wetting...I hope she will be alright in the ward, I wouldn't like to think this has set her back" (girl, aged 3 yrs 6 mths, control group i)

"Of course she is 'trying it on' ...showing off and not doing anything for herself. I draw the line at feeding a four year old!" (girl, aged 4yrs. 6 mths. control group ii)

Negotiating Terms.

Overly compliant behaviours were reported in five children during this pre-admission period, for example:

"He is being very good...long may it last!" (boy, aged 6 yrs. control ii)

"She is just different,,,being so good, it is just not like her. I think she knows she is going to get all the attention and is looking forward to being a bit spoilt"

(girl, aged 6yrs, 6 mths. control ii)

Although the number of children within this category is small and an in-depth analysis of the rationale for this compliant behaviour would be contrived, it is interesting to relate the above to the children's conception of hospital treatment within a developmental context (chapter, 4).

The child may be perceived to be making amends for past imagined misdemeanours in the hope that a reprieve may be negotiable. It is also implicit in the latter comment (above) that some children may expect the event to be a positive one, one which may potentially hold some reward. The 'good' behaviour reported in response to the news of the event may be an anticipation of a later benefit, which may be perceived to be contingent on parental approval of behaviour before the event.

A further point of interest in the analysis of manifest anxiety prior to admission is the report of positive responses in relation to the anticipated event. Although not specifically asked, 6 parents used this question to report how well adjusted they perceived their child to be, for example:

"He is going around telling all his friends about his admission to hospital. I think he is quite excited at having something special happen to him"

(boy, aged 4 yrs 6 mths experimental group - mother is a nurse)

10:5 Discussion of Pre-Admission Coping in Children.

Separation anxiety is a recurring thread throughout the pre-admission discourse. The child is seen to seek reassurance of parental love and close physical proximity during the process of coping with an unfamiliar event. The constellation of responses, elicited by way of three semi-structured questions contributes to the understanding of the process of adjustment as the child prepares to enter hospital to undergo surgical treatments.

Regressive behaviour, implicitly stated to be an indication of the child's failure to cope with the situation is described in the nursing literatures as coping behaviour used by young children to manage difficult situations (Sorenson,1990). Freud (1965) discussed regressive behaviour as a normal function of childhood development used to restore ego strength and master anxiety. Defining a behaviour as maladaptive requires reference to the context of that behaviour as well as to the inter and intrapersonal factors operating within the child at the time. It is apparent that some mothers need help to interpret regressive behaviour as part of the process of coping which is seen in young children undergoing stressful encounters. This will be reviewed in the final chapter in relation to the implications of the study.

While expression of emotion focused coping occurred as examples of behaviours identified by the mother throughout the pre-admission data, few mothers actually perceived this to constitute coping. Indeed, coping was viewed largely in terms of outcome, rather than as a process.

Mothers may also have interpreted crying as a signal for help, a way for the child to obtain the help he needed. This interpretation is consistent with Bowlby's theory of attachment, that is, crying as an attachment behaviour, a way of signalling needs (Bowlby, 1969). The child's capacity to experience particular emotional reactions depends in part, on the development of an understanding of the social context and its significance. Exploring the child - patient role is one example of the child attempting to locate self in the events and actively search for the meaning of the events. The concept of cognitive appraisal encapsulates individual differences in response as seen by the diversity of the nature of the questions asked and the behaviours manifest, thus focusing on the personal meaning of the event. The emphasis on the nature of the questions asked by the children is considerable. This is justified in relation to the insights such data has given in relation to the coping approaches adopted by the child prior to admission. The influence of pre-admission coping responses on in-hospital adjustment and on the parents perceived anxiety is an important one. These issues will be addressed in subsequent sections.

Locus of control has been found by other writers to relate to particular coping behaviours in

the child (La Montagne,1984). Active coping behaviours, for example, information seeking and alertness to the stressful stimuli are found to correlate with internal locus of control (Bishop, Hailey and Anderson, 1987). It is apparent that some children are actively engaged in coming to terms with the meaning of the events while others, employ avoidant coping, associated with an external locus of control.

The data were analysed in relation to the direct responses to the questions asked and then in relation to the variables of interest. On a general level, the pre-school children tended to require reassurance about parental involvement and the duration of the events. While the 5-7 year group actively sought information about the events. This is entirely consistent with developmental theory and embraces the cognitive abilities of the child as well as his emotional response to a stressful event. The child's capacity to experience particular emotional reactions depends on the development of an understanding of the social context and its significance. Capacities for emotional control increase as the child's cognitive processes develop. (Damon, 1977). The cultural and social norms in which the family function are important considerations. For example, one male child in this study is of Asian birth, another of Greek parentage. The expression of emotions reflect the cultural as much as the developmental influences in the child.

Analysis of preparation approaches adopted by the child and parent, suggests that the emotions of fear and anger are expressed more readily in the young child as he attempts to assimilate the events within his existing cognitive schema. The primary role of cognition in emotional expression of the child requires to be addressed when interpreting his responses to aversive stimuli (Lazarus, 1982). This issue, as it relates to the present study, is referred to in the literature review.

The Effect of the Experimental approach to Preparation on the Child's Pre-Hospital Responses

Given that the children assigned to the experimental treatment condition received their preparation three to six days prior to admission, their pre-hospital responses were expected to be influenced by this preparation. This in fact is evident in the comments made by the parents in relation to their child's reaction to the ward visit and the events which took place during it.

27 parents in the experimental group reported that, in their view, the pre-admission visit influenced their child's acceptance of the forthcoming events in a positive way, for example:

"Since he has been in, he doesn't stop talking about it. I think he is really looking forward to the playtime with the other children, ...his questions are mainly about the things he saw, and how he is going to fit into the ward routine" (boy, aged 7 years).

"I am so glad he has had that visit, he was quite determined he wasn't going into hospital but after seeing the ward and meeting the nurses and other kids he realised it was not as scary as he thought" (boy, aged 4 years)

"She told everyone at school the next day, ...a bit quiet when we got home, she did not have much to say on the journey. At bedtime, I got all her wee anxieties and questions. I'm very glad we went I feel I was able to prepare her a bit better after that" (girl, aged 6 years)

It is apparent that a minority of the sample perceived the pre-admission visit as part of the process of the child's preparation, a process which the parent was in control of. Other parents felt that the visit represented the total preparation:

"I am glad we came, I would never have been able to prepare him like that, he seems much better since the visit, much less difficult now he knows what it is all about, I feel better too-

the knowledge that the staff do care about the Mums as well, you don't feel so spare" (boy, aged 4 years)

The three parent respondents who felt their child reacted negatively to the hospital visit had this to say:

"He was so worried when we came away, he kept saying how big it was and would we be able to find him...the little things upset him, the smell of the ward, I think just the cleaning stuff, ... also I think he is worried about falling out of bed, they seem so high compared to his bed at home" (boy aged 4 years)

Similarly, a six-year old girl responded with frank anxieties:

"How can you get out on time (of bed), to walk all the way up to the toilet. I think the playroom is stupid it's for babies"

The implicit contradiction in the above statement is apparent as the child indicates dependency on the one hand and superior maturity on the other. In developmental terms, this is compatible with the need for the child to feel in control of some aspect of the unfamiliar experience. In this example, the six year old is expressing a natural fear of bed-wetting while immediately countering this with assertions of maturity in play preference. In addition a healthy protest at the event *per se* is implicit in this child's response.

The final comment signals the fear of separation from parents .

"I'm not going in there! they (the nurses) won't let you see me, there are too many other people there - anyway there isn't a bed for you (Mum). (girl aged 4 years)

The opportunity for reappraisal of the stressful event is presented to the children within the experimental preparation group. This reappraisal is based on new information gained while the child spent time within the situation, being exposed to sensory stimuli and having the opportunity to ask questions of the staff. Mindful of the literature which points to harmful effects as a result of pre-admission visits (for example, Poster, 1983), the subsequent adjustment of the three children quoted above will be interpreted in the light of an understanding of the negative perception of the pre-admission visit.

A comprehensive discussion of the perceived value and effect of the experimental intervention will be presented when the final questions from the PHBQ and parent responses are interpreted. In addition, the effect of the pre-admission preparation will be considered in relation to the manifest upset and co-operation behaviours of the children during their period of in-patient care.

Attention now turns to the pre-admission profile of the child in relation to his subsequent responses during the events.

10 : 6 Parents Predictions of their Child's Response to Hospital.

Data describing how the parent's expected their child to cope with the events of hospital admission provide a rich source of child and parent uncertainties and attempts at gaining reassurance. They also suggest the expectations of the parents in relation to the child's perceived ability to assimilate the experience and cope effectively with it; that is the discourse conveys the parent expectations in relation to the child coping with the patient role. In addition, parents expectations as a function of their perception of coping as an

outcome rather than a process is implicit in the responses from some respondents.

Reference to the quantitative data, (appendix-table 13) shows that just over one third of parents did expect change in their child's behaviour during in-patient care. Themes emerging from analysis of this discourse are considered to represent two main areas of concern felt by the parent.

a) Predictions of Psychological Upset

The first is that of changes in the child's emotional state. Concern is expressed of the disequilibrium expected and consequently reflected in the child's behaviour during his time in the ward. Interpretation of this discourse facilitates a more insightful view, examples of parent responses will set the scene for this discussion:

"She will be upset at being left alone and I think she will refuse to speak to anyone" (girl, aged 4 years, control ii)

"I expect she will be very demanding and insist on a lot of attention" (girl, aged 4 yrs. 6 mths control i)

"I expect Anna to be very distressed and to want to punish us for sending her to hospital (girl, aged 3 yrs, 6 mths control i)

"He may wet the bed and be very clingy and tearful" (boy, aged 3 yrs 6 mths. experimental group)

"Before the operation will be the worst, she will need a lot of reassurance and not want me to leave her" (girl, aged 5 yrs. control i)

{10 occurrences of this type of comment- generally integrated with other concerns}

Parents are expecting change in a negative dimension. Two principal interpretations may lead to a greater understanding of the above comments. The first is quite simply the literal meaning of the discourse:-

The knowledge mothers have of their own child's responses to a variety of settings , on the whole, surpasses that of others involved in that situation. This knowing is based on past experience of the child, but also on an intuitive knowing, an intangible aspect of parenthood. The importance of looking towards the implicit meaning of a discourse also embraces the knowing of the mother in this situation. That is; mothers may be expressing

their need to be with the child in a time of anticipated stress, as a 'buffer' against the unfamiliar (Poster, 1983). In his study of the effects of hospitals on relatives Menzies, (1981) makes the salient point that hospitals per se are so inherently stressful that families and professionals spend much energy in managing their anxiety.

Being there in the thicket of the situation provides the mother with a realistic way of managing that anxiety. Indeed, studies have shown that parents who cannot be with the hospitalised child experience more exaggerated fears and uncontrolled anxiety than do the parents who are involved in the experience (Alderson, 1990). The presence of guilt is a further factor which may motivate the parents to 'be there'. This important issue will be addressed in relation to parents feelings about the events in a subsequent section. It is relevant to this discussion to raise the possibility that parents may assuage their guilt at the choices made on behalf of the child by becoming actively involved in his care. An interesting extension of this point is the reported feelings of frustration felt by parents when they are denied access to their child during maximum stress points. This important finding is addressed chapter 11. In addition to the natural desire to continue the nurturing role at a time of heightened need; it may be postulated that parents need to feel very close to their child's pain and fear and share the distress, as part of the process of coming to terms with the decision to accept the surgical treatments.

A further point of interest in relation to the expressed need of parents to be involved is the process of socialisation implicit in children's hospitalisation in the 1990's. Staff and society as a whole, expect the parent/s to be involved at least to a minimal extent. An interesting finding of this analysis is that there is no difference in the expressed willingness of parents to become involved between the group (above) who expected change in behaviour during the period of hospital care, and those who did not expect change.

b) Perceived Uncertainty .

The second major theme emerging from analysis of parents expectations, relates to the concern felt in relation to the behaviour of the child within the ward environment. (qu.6) Perceived uncertainty, a judgement about the event or situation, is identified as one of the conditions which colour parents expectations of their child's behaviour during the time in the ward.

Anxiety is expressed by some mothers in relation to how the nursing staff will 'cope' with their child; concern being voiced for the anticipated level of difficulty their child's behaviour will present, for example:

"I'm afraid she is going to create a scene when I go, you have so few nurses and so many young children, I'm sure you won't have the time to sit with her and calm her down" (girl, aged 5 yrs. control ii)

{ 8 occurrences of the above similarly expressed theme}

This response may reflect a mother's plea for reassurance that her child will **not be left unattended** during her distress. Implicit in the apologetic frame of the discourse is the need for parents to **know** that staff, in spite of apparently limited resources, will assess priorities congruent with parental need and expectations. This is also indicative of the uncertainty felt by mothers about what to expect of the environment. The mother is expressing concern that a 'certain standard of behaviour' is expected of the child, conforming to the rules and needs of the institution is implicit in this observation. The mother is expressing her uncertainty about the level of care she may expect for her child while seeking reassurance that this will meet her expectations.

As has been reviewed (chapter 4) social class influences the expectations of parents in relation to all aspects of health care provision. It is interesting to note therefore that the (8) mothers represented in the above comment were all in social class 3 . It has also been noted as a clinical vignette, that parents in lower social groups frequently address consideration of the nursing staff as a preliminary to expressing their expectations. It is often observed that parents within this group will preface their requests in an oblique way, that is by addressing the child, while targeting their request at the staff. For example, mothers were heard to say to their child 'no John, nurse does not have time to ...or, 'I don't think the nurse would let you do that' The issue of social class will be addressed in relation to parents expectations and reported level of satisfaction in the final section.

It is important to note that no respondents from the experimental treatment condition are represented in the above perceived uncertainty.

One respondent indignantly replied:

"Why should there be any change I am going to be here with him day and night"
(boy, aged 5 years, control ii)

This mother clearly considers her presence to be capable of negating the effects of all stressful encounters. It may also be interpreted as this mother's need to be and remain in control of the situation, an active coping strategy. The relationship between parental expectations and subsequent in-and - post hospital behaviours will be reviewed in a later section.

It was also important to sample parent's expectations of their child's responses to the maximum stress points during the experience, that is coping with the objective stress.

Coping With the Objective Stress.

The parents were then asked to consider how they felt their child would cope with the events:- How do you expect your child to cope with the experience of admission and surgery? (Qu. 12)

All 90 respondents expressed their feelings about their child's coping. On the whole, parents who expected change in their child's behaviour during admission, also went on to express disquiet about the child's ability to cope with surgery. In addition, some parents who did not report that they expected change, went on to describe their fears and anxieties in relation to the child's coping with the objective stress.

Two main themes are noted. The first applies to the group of parents who did not expect the child to encounter any difficulty when faced with the reality of the stress:

Taking it all in his/her stride.

"He may be a bit 'girny' but I think he will take it all in his stride" (boy, aged 6 years, control i)

Taking it in his/her stride was a popular expression used to denote the confidence felt by parents that the child would handle the situation maturely and without undue distress. (23 occurrences)

In effect, the parent may be expressing her desire for a particular mode of coping by the child. As reviewed above, this intuitive knowing also has a dimension of uncertainty, which may also represent attempts to reassure the parent of the child's ability to cope without causing undue distress to the parent as well as to himself.

Some mothers offered a caveat before suggesting how their child would cope:

"With adequate explanation... I think he will be just fine"

"As long as I am there with him, he will have no problems..."

"If we can make it an adventure for him..."

"It is, after all, just a wee operation, nothing major like..."

Other mothers made reference to their child's autonomy:

"I think Andrew is quite level headed, he will be just fine" (boy, aged 3 yrs. 6 mths control ii)

"Wendy will cope well, she is a mature 7 year old" (girl, experimental group)

The comments from the two father respondents are worthy of note:

"He will take it all quite well, he does not make a big fuss about these things"
(boy, aged 4 yrs. 6 mths. experimental group)

"Probably a lot more co-operative when I am here . Her mother is too soft"
(girl, aged 7 yrs, control ii)

Discussion of fathers comments.

The little boy (above) who does not make a fuss, may be perceived to be expected to contain his emotional expression of fear, anxiety and confusion. Given that this child had no previous hospital experience and minimal contact with health care, it is suggested that this expectation is an unrealistic one. The need to look beyond the data, to attend to what is being said (Parker, 1990), also involves attending to the intra and interpersonal factors in context. The family dynamics of a single parent coping at home with three children may in fact suggest that the child does have a level of maturity beyond his years and rises to his fathers expectations. Alternatively, a psychoanalytic interpretation may suggest that this child may simply be displaying the behaviour which is clearly expected of him, while suffering the conflicts of suppressed emotion. The second example of the 7 year old girl tends to confirm societal stereotype of the capable father who does not tolerate any nonsense, while the child may either experience a greater sense of security with the father's presence, or alternatively feel much misunderstood by the seemingly unsympathetic stance. In this instance, the mother's visit is likely to be a more facilitative one in which the child is able to express what she feels about the situation. The observed behaviour during mothers presence may therefore be interpreted as more difficult than that seen when father is here.

I Don't know, let's wait and see.

The second theme encapsulates the uncertainty expressed by the mother:

"I am concerned about how he will react after the operation, he is not the most robust of boys: (boy, aged 5 years, control ii)

"I don't know how he will react, he often surprises me, taking to the baby so well after him being the baby for so long" (boy, aged 3 years, experimental group)

"That's just the worry isn't it, how it's all going to be for her. She can't really understand what's going on, different if she felt no well or had an appendix or something" (girl, aged 4 yrs. 6 mths control ii)

"I am really worried, so I expect she will be. I don't know how it is all going to turn

out and if we are doing the right thing" (girl, aged 5 years, control i)

"I am afraid that he will be panic stricken" (boy, aged 6 years, control ii)

*"I know it is quite a straight forward operation, I think he should be okay"
(boy, aged 4 years control i)*

Discussion of Parent perceptions of the Child Coping with the Objective Stress.

It is apparent that the majority of mothers expected their child to cope well with surgery and the attendant events. Maternal presence was considered by many parents to have a moderating effect on the child's responses. In effecting a synthesis of the understanding gained from parents perceptions of the child's behaviour during the events and coping with the stress, the following levels of analysis inform this understanding:

The child's expected response to the threat of the situation. - Mother as a Constant Carer.

The parents' interpretation of that threat is projected onto the child's expected responses. The mothers who base the child's coping as contingent upon the mothers continued presence, are in fact fostering attachment behaviours for reasons which may go beyond the immediate needs of the child in hospital. It is unhelpful and artificial to fragment the experiences and the factors which may influence them, when a child enters hospital. Within the context of planned paediatric admission, the mother may be seen to be expressing a desire to remain in control and be actively involved in her child's care. Mother as a constant carer is an important theme which will be re-addressed in the light of the expectations held by mothers in relation to parent/staff co-operation. Implicit within this understanding is the effect of the emotional contagion theory. Some mothers assumed that because they felt anxious and upset by the events, the child would also experience distress to a similar degree. As will be explored in the next section, this was not invariably the case. 'Contingent coping' in relation to other support also emerged as an important issue addressed by some mothers. This largely took the form of avoidant coping as evidenced by the caveat 'as long as we can make this an adventure for him/her'.

Intuitive Knowing - a Recurring Dimension of Parent Predictions.

Parents tended to use their past experiences of the child's responses to predict the coping outcomes of the hospital experience, regardless of the lack of previous hospital related stressors. The expectation of consistency in coping behaviour across situations and events is

an unrealistic expectation (chapter 2). It is suggested that parents need to feel secure in their predictions of the child's responses, partly to meet their own needs for familiarity in the face of anxiety, but also as an expectation perceived as being imposed by the staff, for example, several mothers were recorded as saying: "I *should* know, after all I am his/her mother, but this is such a different situation..."

Maternal Attempts to Normalise the Situation and Events.

A further important dimension relates to the mothers attempts to normalise the situation. Reassurance is given of mothers continued presence and the 'simplicity' of the procedures is referred to by (5) mothers. As the later transcripts will show, this reference to the 'routine' nature of the operation masks the real fears experienced by some mothers, particularly in relation to the anaesthetic.

The preceding section had addressed the research question in relation to understanding the child's responses before admission. The remainder of this section will be devoted to an interpretation of the responses made by the child during the period of in-hospital care.

Attention now turns to the actual responses made by the children during their time in the ward.

10:7 Manifest Upset and Co-operation During In-Patient Care.

The data presented in this section reflect the child's responses during his time in the ward and therefore span the admission process through surgical treatment and post-operative care up to the point of transfer home. The rationale for the concept of 'maximum stress points' and the description of these categories is presented in the Method's chapter.

The summary score (p. 184) presents a condensed conceptual view of the responses made by the child during surgical treatments. It is important to look behind this summary score to the narrow conceptual window of individual item analysis in order to gain the wider understanding sought from this analysis.

It is recalled that the quantitative analysis showed that overall, on the basis of ANOVA of the summary scores, a distribution which suggested that control group ii were less manifestly upset than the experimental and first control group. However, it is important to look more closely at group responses to the maximum stress points identified throughout this study to effect an understanding of the impact of the experimental intervention.

This shows that the experimental group were less overtly upset during the maximum stress points, for example, during transfer from ward to operating theatre and during induction of anaesthesia. (appendix -table 12).

This is an important finding. Empirical evidence in the medical literature highlights the dangers to the child's physical well-being and safety, when anaesthetic inductions take place during periods of extreme upset (Gough,1990). In addition, the fear of anaesthetic is considered to be a factor in the child's subsequent response to medical stressors. Melamed and Seigal (1982) report the child's failure to discriminate between aspects of hospital treatment, where all treatments are subsequently perceived in a negative light following a traumatic experience.

The relationship between age and upset during transfer to the operating theatre ($p = 0.0015$) shows that the younger child, in the absence of a parent perceives the event to be outside his control and responds with manifest upset (appendix-table 11).

Separation distress also shows a significant finding. ($p = 0.017$). This represents parental absence at night-time settling. Age differences at this time were found not to be significant. The experimental group, while showing some upset, demonstrated no incidence of extreme upset during this time, while the control groups did experience extreme upset.

Some comments from the 'blind' observer ratings, documented as additional non-category responses, reflect the trauma of the events experienced by some children.

The following interpretation is based on the comments appended by the nurse observers to the manifest upset and co-operation scales.

Nurse Observer:

"...was very distressed, she seemed unable to accept her pre-med, and required a nurse to sit with her until induction time" (girl, aged 4 years control i)

"...kept spitting it out, unsafe to give more pre-med, very distressed, mother left about this time" (boy, aged 5 years control ii)

"Completely hysterical when Mum left, there was no way he could take an oral pre-med- none given" (boy, aged 3 yrs. 6 mths control i)

Co-operation with pre-medication showed 60% (54) of children co-operated fully, while 40% (36) experienced some difficulty. Of this 40% twenty eight per cent were children in control group i. The remaining 12% were distributed across the other two groups. Oral premedication is preferred in this speciality, where the anaesthesia is expected to be of short duration, the premedication given is therefore 'light'. It is important that children are recovered quickly from anaesthetic to safeguard their airway from the risks of inhalation of blood from the tonsillar bed.

Nurse observer went on to comment on the child's transfer from the ward to the operating theatre:

"Quite devastated when she realised her mother was gone, Gill was deliberately misled by her mum" (girl, aged 4 years, control i)

*"Unable to calm her, very distressed, kept crying for 'Mummy'"
(girl, aged 3 yrs. 6 mths control i)*

It has been noted above that there is a significant age difference during this time (appendix-table 11), younger children are more overtly upset than the over fives. The clinical importance of this finding requires to be reviewed. Given that the parents are expected to leave the ward prior to the child's transfer to the operating theatre, the effect of the parents continued presence up to the point of induction can only be the subject of informed speculation. Responding to the data, an integral part of analytic discourse, leads the writer to review the nursing and social importance of parental absence during maximum stress points. Previous studies present equivocal findings (chapter4). Some findings advocate the continuing presence of the mother (Wolfer and Visintainer, 1975, 1979), while other investigators report a higher incidence of unco-operative behaviour during maternal presence (Davenport and Werry, 1979). This latter finding is then interpreted by professionals as a contra-indication to maternal presence during maximum stress points (Pruitt and Elliot, 1990).

The issue is clouded by this 'either or debate'. Reference to the role of the mother during medical treatment has been reviewed (chapter 3). If we accept that in the majority of situations, the child and on the whole his parent, benefit from being together then the focus may change from assessment of immediate responses to an awareness of the subsequent effects of parental absence during maximum stress point of an aversive encounter. Consideration of the staff perspective finds many professionals in favour of the principle of parental presence, but unable or unwilling to implement the changes required to effect this (NAWCH, 1988). As the post-hospital responses will show parents unanimously viewed their absence during these times as problematic, variously describing a sense of failure and or, acute anxiety.

Induction of anaesthesia, as briefly stated, showed a significant finding, with the experimental group experiencing less manifest distress during this time. It is important to recall that all children are routinely taken on a visit to the operating room at a controlled

point during the admission procedures. Therefore all children have observed the non-threatening parts of the equipment (needles and other frightening instruments are kept out of sight) for example, the 'gas machine' and the operating table, as well as exposure to the sensations of smell, sound and space. Masks and gowns are also shown to the children and a theatre nurse, suitably attired, routinely pays a visit to the children during a time when the parents are expected to be with them.

Children within the experimental group, although overall less distressed than the control groups, did also show 1 example of extreme resistance to induction. This child was under five. Comments from the anaesthetist which describe the behaviour of the children identified as being very upset during the induction are now discussed.

"We need to work on this a bit more, as I have said, the nurses do their bit, the parents need to be better informed"

Consultant Anaesthetist.

The Parent's Role - Whose 'Failure'?

The comment from the Consultant (above) highlights some important issues. The onus on the parents to prepare their child is firmly stated. In effect, this doctor is saying that if the nurses are doing their best to prepare the child for the event, any problems encountered during maximum stress points must reflect parental inadequacies. This is clearly a very superficial and inadequate rationale. The factors which influence the child's responses to hospitalisation and surgery have been the subject of the comprehensive literature review (chapter 3). Identification of a single factor of influence, attends only to a part of the whole. While the parents are of paramount importance in the preparation of the child, other factors serve to influence how receptive the child may be to parental preparation initiatives. The possible beneficial effect of having a parent with the child at the point of induction was not raised by the example given above. Personal communication reveals that the anaesthetist is ambivalent about the presence of parents during this procedure. The reasons being the variability of parental ability to handle the situation, coupled with the difficulty of knowing about parental coping dispositions in advance (Hudson, 1990). Given one child identified by the anaesthetist as being extremely distressed was prepared within the experimental treatment group, the effect of maternal absence during the critical 'hand-over' period requires to be considered.

Individual^{*} case analysis, although a daunting task, is required to adequately address the variables raised by the anaesthetist. The importance of securing a calm and relaxed child prior to induction has been reviewed (Gough, 1990). In addition, the effect of subsequent medical or dental treatment involving anaesthetic techniques is empirically stated to be

influenced by the first experience of the child, and this influence may extend well into adult life (Seigal, 1981).

Attention will now be given to the child's responses during the maximum stress points of the experience, prior to addressing the influence of the experimental preparation on in-hospital adjustment.

Resistance to Induction - Variables of Influence

Age was not a factor of significance in resistance to induction, sex however appears to be, although not to the level of statistical significance. Twenty eight per cent more boys than girls were reported to show mild resistance to induction, while of the 9 children who showed extreme resistance, 6 were boys. No definitive statements can be made about gender vulnerability on the basis of the above small sample. Rutter, (1989) in his work on protective mechanisms identified predominant patterns of behaviour in response to stress, these patterns are gender specific. It may also be postulated that the 'bravado' front presented by some boys understandably collapsed when faced with the reality of induction. Further analysis in this present study went on to look at the influence of social class and parental preparation, particularly whether parent or child initiated. A higher percentage of children who showed resistance were in social class 3 (manual). No real differences were noted in the nature of the questions asked by the children who went on to experience difficulty during induction. When integrated, the parts comprising the whole suggest that while some mothers were unwilling or unable to realistically prepare their child for the events, other factors operate within the context of maximum stress points to influence child responses. The three children who interpreted the pre-admission preparation negatively were all upset to a degree by anaesthetic induction. One child experienced extreme resistance, while the other two children showed mild upset during this time, all three were under five years of age.

Post-Operative Settling

An age-related difference in post-operative settling ratings was found; that is consistent with past studies (Meng and Zastowny, 1982), the younger age group were more upset during the immediate post-operative period. Comments by the nurse observers added presence to this finding: for example:-

"Leanne required sedation to settle... just kept crying for her mother"

(girl, aged, 4yrs,6 mths control ii)

"Very difficult to settle, has quiet periods,then wakes up realising mum is not there" (boy, aged 4 yrs, control i).

"...Unable to accept reassurance, pain control and comfort not effective, constant nursing presence required" (boy, aged 3 yrs, experimental group)

The above children also experienced mild to extreme resistance to induction and had difficulty accepting their pre-medication. Interpretation of the comments made by the experienced nurses leads to an understanding of the degree of distress felt by some children during the immediate post-operative period. The presence of pain on swallowing is considerably worsened by crying. In addition, the danger of fresh bleeding is heightened if the child increases the pressure in the tonsillar fossae by crying. The effect of the presence of a parent during this particularly vulnerable time can only be speculative. No studies have been conducted which compare the need for the administration of controlled drugs during the post-operative settling period with mothers presence. However, as will be explored during the final section, the responses from the parents clearly show that their absence during this time was perceived as a source of considerable anxiety and discontent.

Children's Post-operative drinking.

No children within the experimental treatment condition experienced extreme resistance to post-operative drinking and eating. There was a slight age difference in that the older children did show more mild to moderate resistance in the early post operative hours. This is consistent with the older child's level of cognitive development and the association he is able to make between the act (drinking) and the outcome (pain). Children who did experience extreme resistance were examined in relation to the other variables of in-hospital adjustment. It is apparent that there is *no* consistency across maximum stress points in that some children responded adversely to anaesthetic induction while others found post-operative settling or drinking more problematic.

The effect of Mothers' Presence at other times.

Each child was accompanied to the ward by a parent (88 mothers and two fathers). Where the mother was present, 35% of fathers also appeared, usually later in the afternoon. On morning admissions few fathers were able to accompany the family. The presence of the parent during the routine admission procedures was 100%. The effect of parental presence proved positive during the preliminary procedures. These procedures were non-invasive and posed little threat.

In addition, the child is asked to wear a bracelet to ensure correct identification. This is particularly important since it is not unusual within a children's ward to find two children

with the same or similar surnames. Prescriptions are determined on age, height and allergy criteria, as well as with reference to the child's medical condition. Wearing the identification bracelet at all times is therefore essential. Nurse reports indicate that five children resisted the application of this identification. Parents were observed to cajole and persuade to no avail. Nurse, having tried many approaches, including giving one also to 'teddy' and to the parent, made the decision to leave the procedure until a later time. The distress of these children in relation to the wearing of a bracelet presents an interesting insight into the perception of the symbol represented by this. Beuf, in her critical appraisal of the procedures to which children are exposed during hospitalisation cites an example of a child who, although 12 years old, had difficulty accepting the wearing of a bracelet. The following conversation between mother and child is reported verbatim:

Mother	"He just hates these things, I don't know why, he just hates them"
Child	"I know how to get it off"
Mother	"Come on now, you will be out of here in a few days"
Child	"If I bit it off, I would be out of here NOW"

Quoted in Beuf, 1989, p81.

The children who resist the wearing of the 'institutional identification' correctly perceive the association between the bracelet and their imposed stay in hospital. The child feels vulnerable and unable to influence the present events, but they can lodge their own protest. Thus the child is actively engaged in coping with a situation, despite his feeling of loss of control over the outcome. A further example of the role of symbolic literalism is observed as the child associates the bracelet with enforced admission to hospital. The action of the nurse to stand back and allow the child time to accept the necessity of such procedures is, given appropriate parental and child support, an appropriate way for the nurse to cope with a situation of increased challenge. No children within the experimental treatment condition experienced upset during this, or any other admission procedure.

First night settling with and without parental presence was examined in the individual item analysis, no significance was found. Generally, the younger child did not experience any greater difficulty settling at night when parents left. A group difference was apparent however in that the first control group experienced less difficulty settling during parental absence. No extreme upset was reported for the experimental group, but was recorded for both control groups.

The influence of social class, parents attitude towards preparation, and the effect of the child's pre-hospital personality was also reviewed in relation to parents presence. It proved difficult to come to any definitive statement about this variable, since parents

generally 'came and went' and parents who left at settling time, sometimes returned to the ward at a later time to sit with the sleeping child. Also, the expressed desire of all parents across all groups to be involved in the child's care renders further analysis of this variable unnecessary. However, attention will focus on the relationship between intention to participate in the child's care and a review of what the parent actually perceived herself to be doing. This is discussed in a later section. A summary of the effects of mothers' absence during the 'maximum stress points' is now discussed.

Discussion

Hall, (1987) asks the pertinent question:

"At what point in the functioning of the institution, do staff become subservient to the outdated policies of that institution?" (p. 726)

If nursing staff question the rationale behind practices which are observed to cause distress to the child and the parent, care of the individual would become more of a reality. The philosophy of caring which places the perceived needs of the institution in terms of the smooth and efficient running of the ward, above that of the needs of the individual family, can best be described as provider defined. Parents are considered to be a valuable asset to the child after the trauma of surgery. However, even the most insightful of nursing approaches has clearly failed to take account of the distress caused to the child, when he wakes from anaesthesia to find no parent present. The rationale for keeping parents away during the times discussed is twofold: First, the physical reality of the lack of resources; that is the absence of an anaesthetic room in the ENT theatre. This necessitates the child being conveyed directly onto the operating table from an adjoining room, where all children wait with a nurse, who plays music or shows a cartoon video during the waiting period. The children leave this area one by one to undergo surgery. Some members of the senior medical staff are of the view that to have mothers present at this point would cause greater distress to both mother and child at the point of separation and render surgery a greater risk (personal communication, Cowan 1990). The second point relates to the manner in which the operating lists are conducted. The children arrive back in the ward at 10-30 minute intervals and have all returned within 2-3 hours.

The presence of parents would therefore have to take account of their child's place on the list. This is a difficult issue to clarify since lists are frequently changed at the last minute. The effect of parental (usually mother) presence has been studied in a variety of dental and medical settings (Melamed and Seigal, 1980, Venham, et al 1977). Those who advocate the presence of the parent suggest that he/she has a positive influence,

primarily by inhibiting anxiety in the young child. Conversely, those who suggest that parents should not be present during treatments argue that parents have a negative influence on the child's behaviour by interfering with the procedures and by communicating their anxiety to the child. Venham, in his study of children in dental settings concluded that the key variable appears to be the quality of the previous mother child relationship and her specific behaviour in the setting rather than her presence or absence. Rodin, (1983) adopts the view put forward by many who are actively involved in paediatric health care; that is, a child needs his parent at times of particular stress. Admission to hospital for surgical treatments represents such a stress. Few would argue with the findings from the 1988 NAWCH report which state that the nurse has a professional commitment to ensure that everything is done to facilitate parental presence when a child must be admitted to hospital.

Few barriers are insurmountable, if the staff are clear and motivated in their intent to mitigate child and parents' distress. One has to ask if the barriers are human rather than environmental. This is a controversial area and will be further discussed in the final chapter in the light of parental responses which indicate satisfaction with the process of paediatric admission and surgery. Implications for policy and further research in this area will also be explored.

10:8 Summary of the child's In-Hospital Responses.

The effect of key variables on manifest upset and co-operation are now reviewed:

1. The Experimental Intervention

The responses of all children across all groups have been studied in relation to the effect of the treatment condition as well as other important variables, for example, age and social class. While the quantitative analysis failed to show significant findings, the illuminating power of the qualitative analysis paints a different picture. The children within the treatment group did cope more adaptively with key areas of the maximum stress points, for example, anaesthetic induction and co-operation with post-operative treatments. The absence of extreme upset in the experimental group during these maximum stress points signals some difference within this group. Given that the key confounding variables have been addressed across the groups, attention turns to the efficacy of the experimental intervention when explaining this groups 'better' adjustment during the times of maximum challenge to the child. This issue will be further informed when the post-hospital outcomes are interpreted in the next section.

The reports made by the nurse observers on the behaviours observed during the period of hospital care suggests a dimension that transcends that of the measurement scale used as a

tool in their observations. The nurses' knowledge of the child's total responses provided insight into the nature (and supposed reasons) for the extreme responses made. The absence of a parent during the maximum stress point again emerges as an important factor of influence in the level of distress experienced. The relationship between the expectations of the parent's and the child's subsequent coping behaviour is now reviewed.

2. Parent expectation of the child and the child's subsequent coping behaviours.

Analysis of parent expectations in relation to the child's subsequent responses presents a rich contrast. Most of the behaviours described by the mothers in anticipation of their child's adjustment viewed coping as an outcome, rather than an evolving process. Individual case analysis was undertaken for the children who elicited extreme responses to any of the events comprising admission and subsequent treatment. In addition, parental expectations were reviewed and those parents who did not expect change in the child's behaviour during in-hospital care as well as those mothers who expected the child to cope 'maturely' with the events are compared with the child's actual responses.

Extreme Responses and Parental Expectations

Of the children who displayed extreme responses to any aspects of in-hospital treatment spanning the admission process to the post-operative treatments, more than half (54%) were considered by the parent to be well able to cope without undue distress. The key time which represents this dichotomy is that of the immediate post - operative period, which it will be recalled, necessitates giving nursing treatments during parental absence. It is apparent also, that many parents, although accepting the limitations at a practical level, did not appreciate the emotional implications of not 'being there' immediately after the operation. This point is emphasised in some comments made by mothers when they refer to the effect of their absence (p.240). It is apparent from this analysis that mothers view coping as an outcome; that is the degree of adaptational success or failure, considers only those compliant behaviours as representative of 'successful' coping. In fact children who displayed resistance to the procedures were demonstrating an active coping strategy, one which in the context of hospital care was interpreted in a negative light, not only by mothers but also by the nurse observers (p. 234).

The Mature Autonomous Copers

Children who were perceived by the parent to be mature and able to cope with the situation were studied as a small sub-group. Clearly, some overlap in the responses to the category described above was found. All children within this small sub-group (8) were variously upset or very upset during the administration of the oral pre-medication, first

night settling, first parental absence, transfer to the operating theatre and during induction of anaesthesia. The interpretation of this finding leads to two possible avenues of understanding. The first is that the parents simply used past experience as a guide to the child's ability to cope with the event in a manner perceived by the parent to be positive. As has been reviewed, the stress and coping paradigm on which this study is based (Lazarus and Folkman, 1984), views this as an unrealistic expectation since coping is situationally and temporally specific.

The second interpretive dimension relates to the needs of the parents. The parent may have expressed predictions which, at a time of heightened anxiety, were congruent with their desire to believe that the child would handle the situation in a predictably positive manner. The role of unfamiliarity during paediatric hospital treatments is frequently discussed in relation to the child coming to terms with the unknown. Parental unfamiliarity embraces many more aspects of the experiences, (including uncertainty about the child's likely reactions) and is identified as being a major source of anxiety (Martin, 1975).

Parents who did not expect behaviour change during in-hospital care.

This question was asked again at the point of the child's admission therefore a full responses rate was subsequently secured. Although 33 (n=90) parents expected change during their child's hospital care, many more parents went on to say that they would expect change in the child's behaviour on return home. Identification of the parents who did *not* expect change in their child's behaviour led to some interesting findings. All children were upset to some degree during the identified maximum stress points. However, only a small number of the above group experienced extreme resistance to any of the procedures (4). It is noteworthy to recall the comment of the parent who explained her positive expectations on the basis of her 'being there all the time' (p 229). In the event, this was not possible. The child seemed quite accepting of her absence and did not display any extreme upset during the events. Parents predictions, although not entirely fulfilled, were to a large extent realised. This will be reviewed again in relation to home adjustment in a following section.

Parents who did expect change in their child's behaviour.

The parents in the sample who expected change, did on the whole, give fairly accurate predictions. At some point in the array of procedures and treatments, all children within this group experienced some degree of upset. However, the extent of the upset was found to be less than the parents predictions. Martin, (1975) reports a similar finding in her study of parents' perception of uncertainty during the child's hospital treatment. Martin's study

concludes that parents display a tendency to report the most gloomy predictions to the nurse in the expectation that the child will fair better than predicted. This in fact may be the case in some situations but at the level of analysis, remains a superficial finding. The need to address the family and situational variables as well as the mother /child relationship within the context of the stressful event is necessary to gain a greater understanding of the motivating forces which govern parent predications of their child's coping.

I was intensely aware at the outset of this analysis that interpretation of the discourse was not simply a question of focusing on the hospitalised child and comparing his pre-admission behaviour with that of his post admission adjustment. How the individual child copes with the stress during admission and surgical treatments depends also on his or her current personality development and the quality of family relationships and support in particular. The child's experience within the hospital is also considered to be crucial in determining his post hospital behaviour as well as his subsequent responses to medical and social stressors (Garmezy and Rutter, 1983). In addition, the influence of previous stress requires to be considered as the child recovers from an experience which has physical and psychological sequelae.

A particular sub-analysis looked at the child who had recently lost his father during an operation. This child's mother was seen to foster the role of the child as a mature boy (6 years old) who had assumed a protective role towards his mother and younger sister. In effect this child coped with quiet resignation. He was the subject of some concern to the nursing staff because he *appeared* to be coping so adaptively. Literature which studies the effect of loss on children has reported age at the time of loss as a crucial variable (Karoly, 1982, Rutter, 1989, Lindsay and Powell, 1989). This little boy was reported by the nurse observers to be :

"Just doing everything we ask, not complaining and not showing any upset at all"

When further probed, the nurse was able to confirm that this child was not withdrawn, he appeared to communicate well with the staff and to other children and had a warm welcome for his mother when she visited. This child was effectively meeting the expectations of his family and the perceived expectations of the nursing staff. The staff were later reported to say that they would have felt happier if he had protested or shown some emotion in response to the stressful events, rather than being such a 'good' child throughout the admission. This intuitive knowing as a dimension in the responses of

the nursing staff to a situation interpreted as emotive, reflects the expectations of the staff in relation to chronological age and the factors within the child's ecosystem. It may also be postulated that the staff were particularly involved with this family as their need for support was perceived to be greater than that of the majority who were considered not to have suffered major stresses in the preceding year. Interpretation of this 6 year old boys' pattern of behaviour can be viewed as positively adaptive in that the child was coping with the situation in his own way. The pressure to do so was implicit in the pattern of family dynamics following the major loss and subsequent life change. An alternative interpretation may be that the child was suppressing his emotions to avoid upsetting his mother, or to feel a sense of having 'let her down' at a time when she too was anxious. In effect, the child may have been responding to the needs of his mother in this situation and to all accounts he met these needs. The comments from the parent in response to questions relating to overall coping and satisfaction with care will further inform this issue. The emotional involvement of the staff in this family is apparent as we consider the demographic data of the sample. Twenty six families were either in the process of divorce, were separated or had divorced. No *particular* attention was given to this group, the effect of divorce was not interpreted by the nursing staff as a particular stressor. The post-hospital adjustment of the sample will now be reviewed.

10:9 Post Hospital Outcomes.

The data considered in this section is drawn from the PHBQ summary score, as well as from two specific open questions which ask about the parents perceptions of how the child coped overall with the experience, as well as data which ask about any changes for the better observed since the child returned home. The PHBQ has been analysed in section 1. Reference will be made here to these aspects of the quantitative analysis which further inform an understanding of post-hospital outcomes.

The data presented further informs the understanding of the research questions which ask:-

Will the incidence of post-admission emotional and behaviour problems be influenced by the nature of preparation for paediatric hospitalisation and surgery? and,

Will the children who find the experience of hospitalisation and surgery a positive one, be more likely to have been prepared for the event within the experimental treatment condition?.

As a preliminary to the discourse on the above aspects of the experience, it is necessary to review the parents expectations in relation to changes expected in the child's behaviour upon his return home. The quantitative data shows 57 (62%) of the parent respondents expected change, with the expected change in the experimental group higher than that of the control groups (appendix-table 14). It is recalled that this question was asked at the point of the child's admission to hospital and the experimental treatment had taken place. Attention is drawn to the expectation across groups, of change in the child's behaviour during the time in hospital. In this instance, the experimental group expected change to a similar (low) degree to that of the control groups, although the limited response rate renders interpretation of this finding less meaningful.

As a preliminary to analysis of the discourse which represents the post-hospital responses of the child, it is illuminating to ask 'what did the parents expect of their child after she/he returned home'?

Parents Expectations of Change in the Child's Behaviour after Hospitalisation.

The expectations generally fall into two main categories. From these categories, themes emerge and a higher level of integration is possible. Interpretation of the meaning of the changes within the context of child -in -family coping with in-hospital care will be developed. The key variables identified as influencing parents' expectation of post-hospital change include the child's previous experience with stress, parental anxiety, age of the child, relationships within the family, staff/family interactions and preparation for the events. These changes are summarised within the following two main themes:

1) Responses which reflect the child's psychological adjustment .

Child and Parent Coping Responses.

Indications of the parents anticipation of an adjustment process are implicit in some responses, for example: (29 occurrences of this type of response)

"I expect him/her to be clingy and possessive"

"I expect him/her to be attention seeking and afraid to let me out of sight"

"I expect all sorts of 'playing up' and the need for extra attention and care"

Parents are implicitly suggesting that;

- a) they expect there to be a need for a time of adjustment and
- b) the first few days are the critical time in this process.

Parents may also be preparing themselves for the additional demands such behaviours

may impose on them. This is articulated by a few parents: (6 occurrences along a similar vein) for example,

"I can see we are going to have to be very patient and put up with all sorts of bad temper, and demanding behaviour, after all the attention he/she has had in the past while" (girl, aged 4 yrs. control i)

Other parents made reference to the discontinuity caused by the experience and the need for time for the child to feel sure of his home routine again. (10 responses within this group - mainly children under 5 years)

"I would expect her/him to be more difficult, after all...this is a very upsetting thing in a young child and he is bound to feel a bit unsettled and wondering what is going to happen next."

Comments indicating the mother's desire to find a cut-off point are also recorded.

"...As long as he/she doesn't expect all this attention for too long after getting home, there is the baby/other children to think of as well"

"...and yes. I would expect her to be more difficult...knowing we are more tolerant until she is fully recovered"

The above comments present an inherent contradiction. While some parents are aware of the possibility of psychological upset following hospitalisation, this upset is expected to be very short lived. Interpretation of the above discourse suggests that the mothers expect the child to consider the needs of the other family members during his recovery phase. This is largely interpreted as an unrealistic expectation during the recovery phase of a stressful experience. While children may be able to 'decentre' at an earlier age than Piaget believed (Donaldson, 1986), the effect of admission to hospital and the traumatic experiences encountered during the stay will, in some children result in regressive behaviours in the post-operative period.

Other parents focused on specific aspects of the experience as likely causes of post-hospital upset:

"I think he will be very angry with us for letting him have an operation which leaves him feeling sore and miserable, after all. look at him now, he is perfectly happy..." (child playing happily with peers in the ward playroom - boy, aged 3 years, control ii)

"He will be a bit aggressive when he is feeling sore"
(boy, aged 5 years experimental group)

The tendency for parents to focus on the tangible aspects of the experience; that is the associated post-operative pain, provides them with a concrete reason for the child's expected level of distress and the concomitant level of parental care predicted as being required. This represents a further aspect of parental coping in that prediction of the outcome (the child's pain), does, for some parents serve to aid coping with the events and to a lesser extent to deflect from the wider issues of psychological upset by focusing on isolated predictable reasons for that upset.

The expectations of the child's ability to manipulate the situation to his own advantage was also included in the comments made: for example:-

"I can see she is going to make the most of all this, she will expect to be pampered at home after all the attention you girls seem to be giving her in here"
(girl, aged 6 years control i)

Parents may also be implicitly saying that this anticipated behaviour is also a necessary part of the adjustment process. In some ways, mothers are looking upon the post-hospital period as an opportunity to compensate for the experience they 'have exposed' their child to. It may also be postulated that negative behaviour on the part of the child, which demands more of the parents in terms of tolerance and care, help to assuage this guilt; that is the need for parents to balance the equation of parent action causing child upset, mitigated by concentrated parental care during and following the experience.

A further insightful comment was made by a mother of a three and a half year old boy:

"I think he will be very easily upset, it will take him a while to get his confidence back" (control i)

The effect of traumatic experiences on the child's self-confidence and self esteem are more profound when the situation is unfamiliar and support is inadequate (Thompson, 1986). The studies which have investigated the effects of the child's hospital admission on his later self esteem, generally conclude that lower self-esteem coupled with high dependency is a frequent finding in post-hospitalised samples (Sides, 1977, Rifee, 1981). This may also be associated with the degree of separation anxiety, and require a time of restoration of confidence in parental presence after being 'abandoned to hospital'.

2) The Physiological Dimension.

In addition to their predictions of psychological upset, many parents addressed the

physical dimension of the recovery process. Some parents inter-related both aspects of recovery but exclusively in the direction of emotional adjustment being contingent upon physical recovery. 46 occurrences represented in the following examples:-

"Of course we expect her/him to be more lethargic, to need a lot of attention at home. Like any operation, it takes it out of you"

"...Also this eating and drinking business, he is going to feel so sore, so how I'm going to persuade him to eat and drink I don't know, you really feel for them when they are no well"

"We think of children as bouncing back after this sort of thing, but they need time to get over an operation just the same as the grown-ups do"

"As long as we get something to help his pain, we will manage better at home"

The physical sequelae of the surgical treatments are anticipated by many respondents. The above comments represent an awareness on the part of the parents of the time required to restore the child to full health. There is an indication of the level of parental uncertainty about the events, implicit in comments relating to specific aspects of recovery. This is apparent in the anxiety expressed with eating and drinking and also pain control at home. This theme which extends that of parental uncertainty developed earlier, will be interpreted in relation to the advice given to parents in preparation for their child's homecoming. This is discussed during interpretation of the parent's responses.

The Relationship between Expectation of Change and Social Class

Fewer parents in social classes four and five report expecting less incidence of change in their child's behaviour following admission and treatments, compared with parents in social classes two and three. This non-significant finding is entirely consistent with the research in other fields which identifies educational attainment, occupation and other social class variables as being influential in the parent's ability to appreciate the process of adjustment involved following paediatric admission to hospital (Hall, 1987). The converse may also apply, in that parents who identify the possibility of change following such an experience, may then project their expectations onto the perceived behaviours of the child, or alternatively, interpret any change in a negative light.

Expectations of Positive Change.

Three mothers reported that they would expect change for the better in their child after return home.

"I expect a big improvement in his behaviour, he should hear better, so after he is over the worst, you know...being clingy and a bit girny, he should be fine"

(boy, aged 6 yrs.6mths. control i)

It appears that this small group are making the direct link between successful surgical outcome and improvement in the child's behaviour. The time lag between the event and positive change is not addressed by the parents. Indeed, there is frequently a period of no change immediately after the procedure, improvement coming only after the effects of the tissue response to surgical intervention has subsided. It is a matter for some concern that the parents do not seem to appreciate this. In addition there is only one reference to the likely occurrence of behaviour upset within this small group. An alternative interpretation may be that this group can cope only with the immediate needs; that is the present demands of settling the child into the ward and coming to terms with the anticipated events. This small group are seen to be choosing a positive focus as an active coping measure.

The effect of the present stress on future medical experiences.

One perceptive parent raised the following point:

"I think this will create a strong impression on him about future medical care"

(boy, aged 4 years, experimental group)

Individual case analysis shows that the mother of this boy had a very vivid recollection of undergoing surgery when she was nine years old. This mother reported that she could still sense the smell of the theatre and has had a 'fear of gas ever since' In fact this little boy coped very well with in-hospital care and experienced little difficulty with post-operative treatments. The experience of the mother during this time presents a sharp contrast, this is looked at chapter 11. This child was therefore, not overtly influenced by maternal emotion contagion.

Discussion of Parent's Expectations of Child's Home Adjustment.

Parents do, on the whole, expect a process of adjustment following the child's surgery. This is reported to be on a physical and a psychological dimension. Reference was made to the child's ability to manipulate the situation, to 'make the most of all the attention' This

represents a level of cognitive activity which goes beyond the developmental stage of the majority of the sample. An alternative interpretation may be that the children are lodging a protest against the experience and are targeting the parents as perpetrators of that experience. The data say a great deal about parental uncertainty and the need for reassurance. An implicit under current running through the responses is that of symbolic literalism, for example, 'he will be fine when we get him home' or 'we are prepared to cope with anything as long as he is home.' This expresses the fear felt by the parent in relation to the safe outcome of the surgery, as well as uncertainty about the child responses when in hospital. The final section to be analysed is that of the actual changes reported by the parent's two weeks after the child's transfer home. It is recalled that the responses are written by the parent on a semi-structured questionnaire (appendix 1).

10:10 Post-Hospital Change in the child's behaviour

As indicated by the distribution shown in the Kruskal-Wallis ANOVA, the experimental group were perceived by the parent to be less disturbed by the experience than the control groups (chapter 9). However, subsumed within this summary variable, lies important clinical and social data which inform the process of children's post-hospital adjustment. The qualitative data presents a wider canvas from which an understanding of this adjustment may be drawn. Attention to the influence of the key variables identified throughout the study is required. While the experimental treatment condition fared 'better' on the summary variable of home adjustment, with control group ii experiencing greater problems, the parents perceptions of how the child coped overall with the experience presents a contrasting picture. This apparent contradiction will most appropriately be interpreted within a discourse analysis framework, which in turn encourages controlled confrontation with differing interpretations within the data.

Parents Perceptions of Child's Coping During the Experience.

Thirty six parents reported that their child coped well with the events, apparently having no ill effects. Eleven children within the experimental group were in this category.

Twenty two parents reported that their child needed comfort and reassurance after the events. Twelve of these children were in the the experimental group.

Twenty four parents reported that the child was very upset by the experiences, six of whom were in the experimental group.

The remaining eight parents chose the alternative response category (open response instead of, or in addition to, response to the question asked), examples of these comments

are now reported:

"He was very upset by the experience, he won't let me out of his sight, he wakes up screaming in the night" (boy, aged 3 years, experimental group)

"He and me, coped better while he was in hospital, he is really clingy and very demanding, I am just exhausted" (boy, aged 4 years 6 mths control i)

"He had an asthmatic attack when we got home, the Dr. said it was due to the upset of it all, he is a bit more settled now, but it is quite a worry" (boy, aged 6 yrs.control i)

"He is absolutely terrified about coming into hospital for his check-up. The GP. says he will do it instead, but I don't know if that will be alright". (boy, aged 7 years, control ii)

"He is very aggressive towards us, very unco-operative and high most of the time" (boy, aged 3 years control i)

"I never thought it would be like this, he is not well and being impossible to cope with " (boy, aged 5 yrs, 6mths. control ii)

The above respondents were all mothers. The two father respondents indicated that their child had 'coped well with the experience'.

Two main areas of concern emerge from analysis of the above discourse. The first is the degree of upset still being experienced by some children 14 days after surgery. The second concern relates to the stress and anxiety to which the mothers are exposed. Implicit in their comments is a plea for help, for reassurance that the observed behaviours are, within context, appropriate. In addition, the extent of physical and emotional exhaustion felt by the parents is generally unexpected by them. Parental concerns will be discussed in the next chapter.

Extreme Upset in the Post-Hospitalised Child

Reference to the child's pre-admission profile and other variables of note, for example, exposure to previous stress, are necessary to effect an understanding of the above responses. Of the eleven children who were considered to be outside the normal range of responses on the pre-admission profile, that is the summary variables, attachment and autonomy and social behaviour, a fair group distribution was found. These children had difficulty coping with in-hospital care and subsequently were either very upset by the experience or

are represented in the comments above which were made by parents who chose to expand on the post-admission behaviour of their child.

The exposure to previous stresses is also important. Of the eleven children who scored higher on the pre-admission profile, nine had experienced some previous stress as reported in an earlier section.

Six children from the eight non-category responses to post-hospital upset had previous stressful experiences, mainly recent family separation, the birth of a sibling and the loss of grandparents. Although a small number, there is an association in this study between previous experience with stress, pre-hospital personality and subsequent psychological upset following hospitalisation.

The Effect of Age on Post-Hospital Upset.

Although the literature generally supports the view that younger children are more manifestly upset by the experience of hospital admission, the findings of this study are more consistent with those of Bothe and Galdston (1972), who found older children equally upset on a range of post-hospital self report measures. The rationale proposed for this finding is that the older child is able to contain his distress while in the unfamiliar environment and conformed to age related expectations. On return home to the safe haven of the familiar environment, the child is able to express his real feelings about the events. A note of caution is raised here about the interpretation of behavioural measures across a wide age range. The danger exists that the appropriateness of the instruments used for assessing constructs such as psychological upset will vary across age levels. The possibility of systematic bias is introduced. What the behavioural indices do in parent perceptions is to compare pre-admission behaviour of the child and document changes in the frequency nature and degree of isolated behaviours typically associated with emotional distress. While the overt behaviours may decline with age, they are supplanted by other more subtle manifestations of upset that are less readily detected by standard outcome measures. The parents reports are considered an invaluable way of circumventing this problem.

The effect of Socio-Economic Status.

The effect of social class was looked at in relation to the parents reports of children's post-hospital coping. The differences found in relation to this variable related more to the manner in which the parent expressed the child's coping rather than discrete differences in coping *per se*.

The Influence of the Experimental Intervention.

The experimental group reported a higher level of 'non-coping' or difficult adjustment on the measure which asks how the child coped overall with the experience (appendix-table 16). One parent respondent from this group used the non-category response to indicate the real nature of the child's adjustment. However, findings from the PHBQ presented in section 1, indicate that the experimental group fared 'better' on this measure. Direct and controlled confrontation as a way of addressing apparent contradictions is a necessary part the analysis of a study which uses combined method. Interpretation of this finding will inform this issue.

The three children who were initially reported to be upset by the intervention subsequently adjusted well (see also 10:8). Parents of this small group went on to express their satisfaction with the approach to preparation received by them (p298).

It is recalled that the majority of the experimental group did expect change in their child's behaviour after hospitalisation. It was postulated that this may be due to the effect of the preparation initiative in providing mother and child with information about the reality of the events. It is possible that because the parents were expecting negative change, the change observed was more likely to be interpreted in a negative light. It may also be the case that a direct focus 'How do you think your child coped...' provided the parent with a forum for expression of the overall effects of the experience on the parent as well as the effect on the child. The effect of the experimental intervention shows a varied response. Some variables, in particular, the maximum stress point, show the experimental treatment group coping 'better' than the control groups, while the reverse is the case with other less central variables. The PHBQ is of value in addressing positive as well as negative changes. Examination of individual variables within this summary score show some interesting trends. All children in this study were reported to be more co-operative with bedtime settling when home, which indicates a positive change overall.

Review of the questions relating to obedient behaviours on return home, show control group ii reporting an increased level of less obedient behaviours. This incidence of disobedience is in keeping with the findings from other studies (Douglas, 1979, Peterson, 1989). It is postulated that the child expresses his anger and feelings of helplessness by presenting his parents with the challenge of unco-operative behaviour. This, in the context of the child's homecoming following a stressful event, evokes feeling of empathy from the parents who generally tolerate extremes of behaviour, attributing it to the 'child getting over the upset'. The experimental group show a modest improvement on this variable.

The literature suggests a correlation between less obedient behaviour and the incidence of loss of temper during the immediate post-hospital period. This is related to the

hypothesis that children need to express the anger and resentment they feel at having been subjected to such a stressful experience (Skipper et al, 1968). No such correlation was found. An alternative interpretation is presented here; that is, when disobedience is viewed as a protest, an attempt by the child to reassert his hitherto threatened position in the family; parental tolerance as a coping measure will negate the need for further hostility and anger on the part of the child. This is seen as an alternative interpretation of the literature in the context of this study, rather than a contradictory finding.

The experimental group also show an improvement (not at a level of statistical significance) on the item, child communication with parent following transfer home.

The item, reaction to strangers show the experimental group reported as less anxious than before. The other groups reported no change.

However, attention to the parents perceptions of the perceived value of the preparation initiative is necessary before the concluding statements can be made about the effect of the experimental treatment on the child's post-hospital adjustment.

While expectation of behaviour change may suggest a parents readiness to expect and subsequently cope with psychological upset following paediatric hospitalisation, the degree and duration of this upset is on the whole unexpected by the parent. Further exploration of this issue will be made in the next section.

Positive Changes Following the Child's Hospitalisation.

Physical recovery was asked as a separate question with the explicit intention of attempting to separate parents perceptions of physical change, reflecting benefit from the surgery, and those changes relating to the emotional recovery of the child (qu.17).

The data describing the child's physical recovery is presented in the appendix (figures 1-2). It is suggested that in addition to the emotional adjustment of the child after the experience of hospital treatments, the physical recovery is important in relation to the effect on the child's behaviour as well as the physical and emotional demands placed on the mother.

It is interesting to note that in spite of a full recovery, the parents in the experimental group kept their children away from school/nursery for a longer period (appendix-figure1-2).

Parents Reports of Positive Change in the Child's Behaviour .

Twenty six (28.9%) of the sample reported a positive change in the child following hospitalisation. This significant finding is presented in appendix-table 18 ($p - 0.006$). It is apparent that control group ii observed more positive outcomes in the child. The additional attention given to control group ii was focused on the child and his day to day activities and general demeanour, and recorded one week before admission. It has already

been suggested in this study that the effect of the additional attention, which it will be recalled was unrelated to preparation, may have stimulated emotion focused coping by enhancing the parents perception of individual care. It is also important to consider the reports of positive change in the experimental group and to reiterate the expectations of all groups in relation to change expected, all of which was negative.

22/30 parents from the experimental group expected negative change in their child / 9 children showed positive change,

19/30 in control group i expected negative change and /1 child was observed to show positive change.

16/30 in control group ii expected similar change / 16 children showed positive change.

The above positive changes were not necessarily found in the children who were expected to display negative change. The incidence of negative changes are reported in the summary AVOVA tables presented in chapter 9.

The following few examples of comments from parents are discussed in relation to the above findings.

"I see quite a difference already, he is much easier, less 'hyper'and will sit and talk to me more". (boy, aged 6 years control ii)

"There is a big improvement in his general health, his behaviour is very much better, like a different child really." (boy aged 6 years experimental group)

"He is quite bouncy really, really happy. Once over the throat infection. He seems to want to be helpful all the time. I wonder if that is him just relieved at being home, long may it last. (boy, aged 4 years, control ii)

"Quite a change really, she is very affectionate and doing what she is told!" (girl, aged 4 years, experimental group).

Discussion.

The importance of positive change following hospitalisation has been well documented (Vernon, 1966, Prugh, 1983). However, the reported change has mainly been described, not interpreted. In addition, change has been observed within the two week post-hospitalisation period only in the majority of studies. This limitation is addressed in relation to this study in the concluding chapter.

Interpretation of the above few examples leads to the understanding of the responses made. The following themes have been teased out from interpretation of this data:-

The Relief Factor.

A pervasive interpretation of the above responses may be the presence of relief at being home, the aversive experience left behind and the confirmation of parental concern at a time when most parents are more attentive and sensitive to the child's needs. It may be postulated then that the positive changes noted in the child's behaviour may be transient changes. The duration of the adjustment process when a child returns from hospital is the subject of much, mainly speculative debate. While many children are seen to 'return to normal' within the two week post-hospital period, the influence of the variables which have a bearing on his post-hospital adjustment is much under-researched. The above data can only suggest some of the factors which appear to be operating within the short time-span from hospital to home.

A Salutary Learning Experience

Given that the concept of hospitalisation as a form of imminent justice has been reviewed and applied to the earlier pre-and in-hospital responses of the child, it is appropriate to consider his responses to homecoming as suggestive of 'having learned from the experience'. If the child does perceive hospital as a form of punishment, then the effect of that punishment on his behaviour is reasonably expected to be positive in some children. The age range of the sample who experienced positive change is found to be distributed across both age groups. Clearly, all communication within and following hospitalisation attempts to dispel this perception by constant reassurance and attempts to help the child perceive hospital treatment in a positive light.

A Real Change in Behaviour.

Consideration of an actual, rather than an apparent change in the child's behaviour requires to be addressed. In relation to the child who had hearing impairment prior to hospitalisation, the change observed may well be a real one. Also some children are thought to reappraise their relationships with their parents after a period of separation (Damon, 1977). It is important to state however that this reappraisal is more likely to be on a negative dimension if the child's developmental stage is more vulnerable to the effects of separation. The issue of pre-hospital family relationships is an important area to consider.

10:11 The Epistemic Link within the Hermeneutic Circle - Child Responses.

The cycle of enquiry moves clockwise and anti-clockwise around the hermeneutic circle of enquiry, as this analysis has sought to understand the stress experience of the child

throughout the events which span hospitalisation and surgery. The concept of psychological upset is interpreted by addressing the findings from the PHBQ (chapter 9) and from the qualitative data presented in this section. Although parents did report behaviour improvement on several items of the PHBQ, these items were not repeated in the parents written assessment of their child's adjustment. The epistemic link is seen to span the process from the pre-admission initial responses through in-hospital care and post-hospital adjustment. Consideration of the many variables which influence the child's responses, and the interaction between them, required that the analysis moved clockwise and counter-clockwise round the hermeneutic circle to effect an understanding of the child's experiences.

10:12 Summary of the Main Findings of Child Responses.

The responses of the children were reported by the parents throughout this interpretation. The issue of personal meaning therefore has been explored indirectly, reflecting in part the parent's perceptions of the child's responses as well as reports of verbatim comments made by the child. The nature of the questions asked by the children as they anticipated admission to hospital, indicated the concerns felt by them. These concerns spanned a wide range of frank anxieties as well as attempts to interpret and find a meaning for the events in which the child found himself inextricably entwined. The children within the preparation group were reported to ask questions which focused directly on the experience as they perceived it during the ward visit prior to admission. The questions asked by the experimental group therefore represented the child's attempts at re-appraisal of the stressful encounter as they were observed by the parent to seek clarification and reassurance that admission and treatment would not necessarily involve the degree of threat which they felt existed, prior to preparation. The three children who were reported by the parent to find preparation stressful *per se* went on to ask questions which indicated a willingness to seek reassurance, particularly of continued maternal presence and the nature of the procedures.

The children in this sample were upset by varying degrees prior to and including admission and transfer home. Data from nurse observers as well as parental reports attest to the diversity of ways in which distress was expressed by the child. The adjustment of the children within the preparation group suggests that the experimental intervention was effective in mobilising coping of the treatment group, who appeared able to assimilate the experiences in an active and non-traumatic way. The experimental group were seen by the nurse observers to be less upset by the maximum stress points throughout the experience.

Given that the sample were matched on as many variables as possible and random sampling secured the group assignments, a pervasive assumption is that the preparation given to the treatment group was instrumental in mitigating the distress associated with admission and surgical treatments.

The post hospital data also supports the efficacy of the experimental intervention. The quantitative data, while failing to demonstrate statistical significance, did show an interesting distribution in home adjustment across the three groups. The treatment group appeared to fair 'better' than both control groups. A different perspective is offered by interpretation of the qualitative data. Parental responses recorded on the post-hospital questionnaire attest to the varying degrees of upset observed in the child two weeks after transfer home. The children within the preparation group were considered by the parent to be more upset overall by the experience. Interpretation of the expectations of the experimental group suggests that the parents expected change to a greater degree and were considered to be sensitive to subtle and covert changes in the child's behaviour. The treatment group also reported positive change in behaviour in the post-hospital period, although not at the same level as control group 2 who reported a high incidence of positive change on return home. Interpretation of these changes by the parent attribute them to both physical and emotional changes following a period of hospital care.

There appears to be a link between the mother's ability to cope with the continued demands, both physical and emotional, of the child after transfer home, and the reported overall adjustment of the child. Only tentative comments can be made about this finding since no further data were collected which would enable clarification of this point; that is, whether the child's distress and continued dependence caused the mother to report her inability to cope with the post-operative care of her child or, conversely, whether the mother's existing emotional state rendered her unable to meet even reasonable child care demands. It is postulated that a reciprocal relationship may exist and that the effect of the hospital admission reached a crescendo when the mother found herself at home coping with continuing care for which she was largely unprepared. This issue will be further explored during interpretation of the parent's responses, to which this analysis now turns.

CHAPTER 11.

ANALYSIS OF THE QUALITATIVE DATA (2)

RESPONSES OF THE PARENTS

11:1 INTRODUCTION.

It was necessary from a conceptual as well as an organisational viewpoint to examine the responses of the parents after analysis of child responses. This was important for two reasons. First, the children are the initiators of the data, that is, it is the children's experience of stress and coping which are seen to subsequently mobilise the coping efforts of the parents. *All responses are reported by the parents.* In addition, the parents are seen to respond to the process of the child's hospitalisation and the attendant events; this is seen to be influenced by the personal meaning of the events, an issue explored in the literature in relation to parental anxiety. This personal meaning is strongly influenced in turn by the perceived adjustment of the child throughout the process. Exploration of the many variables which influence the child's responses was therefore necessary prior to proceeding with interpretation of parental responses. For example, "emotion contagion" as a term generally used to describe the effect of parent's anxiety on the child's feelings of upset, is also seen to be a reciprocal construct (Thompson, 1986), thus addressing the close inter-relationship between child and parent responses in the medical setting .

The focus of this analysis shifts from the reactions of the children to hospitalisation to those of non-hospitalised family members. It is important to re-state that this compartmentalised style of presentation, although conceptually convenient, does not obscure the close and necessary inter-relationship between both data sets. Parental reports of sibling responses will not be analysed in this study. This reflects the limitations of the final length of this thesis rather than the absence of rich and enlightening data.

The very richness of the responses from parents who shared their experiences with me defies simplistic reduction. An important discipline following the early stages of category analysis was that of selecting only those parts of this fascinating and illuminating data which informed an understanding of the coping process and contributed to an understanding

of the responses shared by the parent. In addition, the data presented is also expected to shed light on the research questions. Mindful of the privilege of being able to share these experiences with parents at a time of heightened stress and perceived vulnerability, I intend to use the data not reported in this analysis in papers which will be submitted for publication in clinical nursing and research journals.

Addressing the 'trustworthiness' of my interpretation.

Validation of my interpretation of the data presented in both analytic chapters is addressed in the manner appropriate to an interpretive analysis. In the context of the present study, a systematic search of the data signalled five particular areas to be considered. Firstly, the contextual nature of the research coupled with the extensive nature of the qualitative data contribute to the 'trustworthiness' of my interpretation, as do the openness and detail presented in this analysis. The second point relates to the discipline of discourse analysis ; that is the requirement that the interpretation makes sound common sense, "tells a logical story" (Parker, 1990). Thirdly, the contribution of the researcher as a paediatric nurse, nurse teacher, mother and researcher is seen as parental experiences at different phases of the process are teased out and interpreted in relation to the understandings gained at other levels of the experience. Mindful of the danger that clinical judgements about a particular response may be impaired by professional experience (Lindsay and Powell, 1989) as, with a degree of confidence I seek to make intuitive judgements about a particular response, constant reference to the data sources, to the information at hand, ensures that this analysis reflects the primary goal of this study, that is the respondents' reality, rather than that of the researcher. Rather than resisting the tide of observer bias I recognise my influence on this interpretation and constantly attempt to fully listen to the voice of the text. Colleagues currently engaged in studies at similar stages of analysis, provided an invaluable objective appraisal and independently confirmed the key areas of my interpretation. The fourth consideration is that of reference to the literature. While past empirical studies provide a frame of reference for the internal 'validation' of my interpretation, it is important to address the contradictions which arise and to engage in a controlled confrontation with past findings and also with understandings which emerge at different point in this present analysis. Finally, the invaluable insights gained from colleagues and from parents who read the early drafts of this interpretation lend a degree of objectivity to the interpretations I have made.

The degree to which the above five measures assist in the validation of this interpretation will be the extent to which understanding of the parent and child experiences is enhanced and the coping process identified throughout the stressful

experience.

There is therefore a clockwise and counter-clockwise flow of understandings gained across the child and parent responses as the analysis is seen to flow back and forwards within the hermeneutic circle. The data then comes to a point where the interpretations are 'self validating'. Reference to the literature review (ch.2-4) was made as a theoretical signpost which confirmed the interpretations made. While validation is not an issue in this analysis, it is a factor which I addressed for confirmation of the trustworthiness of my interpretation.

11:2 Parents Response to the hospitalisation of their child.

Interpretation of the data in this section tap the feelings and experiences of the parent from the onset of the stressful experience, that is from the point of the first contact with the hospital through pre-admission preparation, in-hospital care and post-hospital recovery.

Transforming this large data set into a meaningful construct required looking beyond the thematic analysis of the child's responses. It was important to integrate also, the important topics which were teased out, rather than which emerged from, the earlier stages of this analysis. The stress and coping paradigm was central also to the interpretation of the responses presented in this section and is a temporally and situationally specific process. In addition to the core theme of coping, the preliminary conceptual mapping signalled the presence of a number of other 'topics' or 'issues'. Some of these topics relate comfortably to the coping paradigm and may be seen to contribute to an understanding of the coping behaviours of the parents. Other topics introduce additional temporally specific themes, which although related to the coping paradigm, go beyond that to interpretation of other areas of concern felt by parents during the hospitalisation of the child. A coming together of the key themes is expected to ensue in the final section.

The approach of discourse analysis within the interpretive framework selected for this analysis made it possible for the interpretation of this data to progress along a 'themes within themes' approach. The work of this interpretive analysis was therefore to identify those themes which were considered to be central to an understanding of the story the parents were telling and which, in the light of the child responses, contributed to a fusion of horizons as I attempted to answer the research questions.

Although the discipline of imposing a tight structure on this analysis would in my view act as a methodological straight-jacket, I accept the need to address the organisation of this presentation to aid the pursuit of clarity and in order to convey the richness and power

of parental responses.

Analysis of parent's responses is therefore presented in the following way:

Phase 1 - The pre-admission process.

This period prior to admission of the child represents a time of considerable reflection, anxiety and stress for the parents. It is, in many ways a pre-coping period initially, as the parent waits for an appointment to have the child examined by a consultant ENT specialist. From the point of this consultation the waiting period is effectively over as the family then begin the adjustment process and come to terms with the proposed treatment plan in their own way; that this period is a particularly sensitive and crucial one in determining the subsequent coping of parent and child is put forward by this analysis. While the literature addresses preparation for paediatric hospitalisation at length, no reference is made to the potential within the initial clinic consultation for influencing, in a positive way, the attitude of child and parent to the upcoming events. For example, an application of the stress and coping paradigm to an understanding of how individuals respond within the medical setting, identifies initial appraisal of the stressor as an important factor in subsequent coping responses (Lazarus and Folkman, 1984). This data presents many rich vignettes of such early appraisals and the opportunity for re-appraisal in the light of supportive information.

Clinic nurse counsellors are available in some centres to assist the family in coming to terms with more momentous medical and surgical procedures. This facility is not available in the more 'routine' clinics. The issue may *not* be one of coming to terms with the objective stress *per se* since most parents have at least made some reference to the need to have the surgical procedure performed for their child. The data suggests that the issues are more subtle and complex. Interpretation suggests that the key areas of concern are those relating to parental control and parental competence and that the level of anxiety observed in parents across all groups (9:6) is exaggerated as a direct result of *perceived absence* of parental control and the concomitant effects on the parents perceptions of their competence at a time of increased vulnerability. The inter-relationship of these issues with the central theme of coping is explored in this analysis.

Phase 2 - Preparation for and coping with admission. This phase of the process elicits understandings of the parents coping responses prior to and at the time of the child's admission and their perceived needs during the child's stay. The very close inter-relationship between child and parent responses is explored as the discourse is analysed with reference to the understandings gained in section 1 of the qualitative analysis. Coping as a dynamic and evolving process is seen to be influenced by factors prior to and at

the time of the child's hospital admission, as the concerns of the parent shift from those of an anticipatory nature to the more immediate concerns of coming to accept the reality of admission and imminent surgery.

Phase 3 - This phase represents a crystallisation of the parental responses and includes perceptions of satisfaction with each of the stages of the child's hospitalisation. Parents views about satisfaction during each of the temporally specific phases is sought and analysed in relation to group differences. The overlapping themes serve to confirm the trustworthiness of the interpretation and are specifically not reduced to unitary themes since this would distort the temporally specific nature of the discourse. For example, the impact of the clinic consultation is raised in the pre-admission phase and discussed in relation to responses made by the parents during the admission interview. Similarly, the clinic agenda re-emerges as an issue within the satisfaction responses and thus reflects a retrospective appraisal of satisfaction in the light of a positive outcome of the health care. To put the two phases together for the purpose of economy and structure of presentation would lose the impact of the parents post-hospital responses.

11:3 Phase 1 - The Pre-Admission Process.

The following questions were asked at the point of the child's admission to hospital and reflect parental responses to specific aspects of the pre-admission experiences. These responses were recorded and are transcribed verbatim. It is appropriate to begin this interpretation by considering the responses made by the parents during the admission interview, since this phase of the experience encapsulates the imminence of the experience and the parents coping with it. Items recorded on the pre-admission questionnaire will be integrated throughout this section also.

The researchers input (where any) is indicated by Res: = Researcher.

Par:= Parent.

Although the respondents in this study were mainly the mothers, the responses from the two fathers will also be reported where appropriate during this analysis.

The first question explored the effect of the admission on the family as a whole:

Qu:- 'Has this planned admission brought about any change to the family routine'?

13 parents replied that it had, 3 families were prepared within the experimental group the remaining ten families were distributed fairly evenly across the other two groups.

The nature of the changes are interesting from a demographic viewpoint and extend the findings of the quantitative analysis (appendix-tables 5-7) The changes reported were of an organisational and emotional dimension. It is important to address these changes in relation to the effect on parental adjustment to the process of hospitalisation of the child. The following representative selection of comments are presented from the parents who did experience difficulty:

Par: "Oh yes, we have had to organise a child minder for her brother and sister, I think they are a little 'put out' I feel quite happy about that side of things, we know the minder and the children like her, but it 's still a lot of planning and expense. (girl, aged 4 yrs 6 mths control i)

Par: "I have had to take time off work to organise things, so the routine is certainly different. My boss is none too happy about this.

Res: About you asking for time off?

Par: Yes, he is single! it is a busy time in the office and he likes us to take holidays at certain times, to hang I say, I need to be off and that is that! (girl aged 6 years experimental group)

The above comment is a strong statement of the social structures which attend economically active mothers. This is singled out here to present the very real and diverse problems faced by some mothers when they also have to attend to 'extraordinary' care of their children while meeting the demands of an employer.

A further relevant concern is expressed by mothers with younger children and indicates the dilemma which the parent faces when balancing the needs of the hospitalised child against that of a dependent (often breast fed) baby at home:

Par: "Arranging baby care is a problem, so we have had the distraction of that too."

Res: "Do you feel happy about the babies care now"

Par: "Well, you know how it is, you feel torn, the wee one needs me at home and Jo needs me here, we just have to share things out and cope as best we can." (boy aged 5yrs 6mths control i)

Par: "Our other son has had to go and stay with Gran, I'm not sure he looks on this as a treat, I think he feels a bit left out of things"

Res: "Will you bring your son in to see Ruth after the operation day?"

Par: "We will have to wait and see how she is, we don't want her getting any infections" (girl, aged 4 years control ii)

Coping with the practicalities of child admission, a logistical challenge to many parents, is seen to potentially influence the coping process prior to admission, and at a later stage of the experience.

The above responses indicate the additional demands placed on the parent as she/he prepares the child for admission. Reference to the quantitative data (appendix-table 6) shows the important family variables which influence the parents ability to manage the pre-admission practical arrangements. The effect on the siblings of the child's admission is significantly greater in families with two or more children, ($p = 0.0016$). Of the minority group represented in the above comments, 9 had two or more children and 6 of the mothers were in part-time or full-time occupations.

The majority (53) reported that they had some difficulty in organising the practical aspects of the admission process. The quantitative analysis confirmed the presence of similar demographic factors within this majority group. Family size, for example, families with two or more children, together with a consistent finding of economically active mothers within the group were factors which contributed to admission problems. It may be suggested that when the context of the mothers' coping is analysed, factors other than family size, work status of the mothers or the presence of external support appear to operate to influence the coping responses prior to a stressful event. For example, it is evident from some of the comments from the minority group that support from grandparents was available. The parents' attitude toward that support was coloured by the siblings response to being "farmed out to Granny". It is important therefore to address the factors within the ecosystem as well as those which relate directly to the stressful experience. The above responses will be referred to again in relation to parental coping during the events.

The parents were then asked to recall how they felt when doctor first suggested surgery for their child (qu. 11). All 90 parents responded by indicating the personal meaning of the consultation and some parents also made reference to how they or their child might cope with the events.

Personal Meaning - The Initial Consultation

The quantitative data shows that, for the majority of parents (65%), the feeling was one of relief that the presenting ear, nose and throat problem was finally being dealt with.

Acceptance of the surgeons advice was based on two main criteria. The first was the discomfort experienced by the child and the parents' natural desire to alleviate the recurring symptoms. The second criteria of acceptance was based on the effect of the continuing problem on the child's education, that is, repeated absences from school/nursery and or the anxiety about the child's hearing impairment and the concomitant effects on the child's learning. The above criteria are now discussed in relation to the coping approaches adopted by the parents. As indicated in chapter 2, the literature suggests a number of coping strategies, two key approaches are identified from parental responses:

a) Problem focused coping.

The majority of the sample reported unqualified relief at having the problem dealt with. Both father respondents were in this group. Some examples of the responses are presented to lend presence to this discussion:

Par: "I was relieved when the consultant agreed we had to do something..."

Par: "I was glad to have the problem recognised and not be fobbed off with more antibiotics..."

Par: "I respect medical advice, there is no point in going to see a consultant if you don't do what he advises is there?"

The parents above are confirmed in their belief that the procedures advised are necessary. There is no mention of a choice being offered or indeed requested. Implicit in the above comments is the absolute faith in medical opinion. This group are representative of the parents who appear to be actively coping at the outset by directly addressing the rationale for the treatment and seeking a solution to the reported problems.

No real group differences emerged from analysis of the above approach to the initial consultation. There did emerge however, an interesting social class distribution. All parents in social class three (manual) and four, were unquestioningly accepting of the advice, as were some parents within social class two. This latter small group also made reference to the need to take expert advice when it is sought and to avoid wasting consultant time if the advice is not accepted. The 'doctor knows best' adage is therefore not (in this study) limited to the families in the lower social groups.

The second group of parents, (the remaining 35%) while accepting the necessity for surgery at an intellectual level, went on to express a variety of emotional responses to the outcome of the consultation. The relationship between cognition and affect is seen to underly the responses.

b) Emotion focused coping.

Par: "...advised to have surgery what do you do? just accept it and feel sorry it is necessary. I do wonder though if it is right at her age and whether she will grow out of it if we leave her" (girl, aged 3yrs.6mths. control i)

Par: "I felt it was necessary to stop all these painful throat infections, but I felt - and still feel very anxious at the thought of it, so I have had to make it an adventure for Ashley's sake. (girl, aged 4 years, control ii) (Mother close to tears during the interview, child playing happily in the playroom)

Res: Would you like to talk to someone now?

Par: No, I'm fine really it is just saying it all, makes me realise that it is actually happening.

A few parents expressed stronger emotions:

Par: "...shocked! I did not think it would need done, I thought the consultant would suggest waiting a year or so.

Res: Did you ask him about this?

Par: No, I just accepted that it was his advice, he is the expert after all. (girl, aged 6yrs.6mths, control ii)

Par: "...shocked and anxious, but then the doctor explained that he was likely to have the problems for another few years if I didn't let him have the operation, so I decided that it was best to put him through it and just resign myself to the necessity. [my emphasis] (boy, age 3 years, experimental group)

Par: "Everything seemed so routine, they all seemed to know exactly what to expect, I felt we could have been anyone...all that mattered was here is another child with the same problem, we will put her on the list and have it dealt with for you"

Res: Is this not what you expected of the clinic appointment?

Par: Well, it would have been good to have had the feeling that there was time for you...you know I ended up feeling guilty that I was one of such a large clinic all waiting to see the obviously rushed doctors. (26 comments along a similar vein)

It is evident that the consulting surgeon is willing and ready to expand and explain further when he is given the appropriate cues. It is suggested by this analysis that the 'routine' nature of the procedures may in some subtle and unobtrusive way contribute to the lack of appropriate explanations given to individual families. The rationale for this position is that of the extreme brevity of the consultation, which, in itself, contributes to the sense of 'routineness' conveyed to the parent. Of the parents who commented on the brief nature of the consultation, some interpreted this positively, reflecting the problem solving approach to the coping strategy adopted by these parents, for example, "Little time to ask anything, but then there is no need for such a straightforward procedure...is there?" It is interesting to note that the parents represented in this group also experienced some difficulty in coming to terms with the rationale for surgery at the point of the child's admission to the ward.

While accepting that the duration of a communication does not necessarily indicate the likely efficacy of that communication, within the context of the out-patient clinic, where the child and parent may be experiencing their first contact with hospital. The clinic consultation did not, for many parents, convey a facilitative atmosphere in which the family could maximise the potential value of the expertise available. The parents (represented in the above comments) saw the same doctor (on different days). It may be the case that because the first parent did not indicate her anxiety to the doctor, no reassurance was thought to be necessary. An alternative interpretation may be that the clinic climate was in some way different for the parents quoted above. These emerging issues are discussed later in this section.

Further examples of initial responses to the clinic consultation are presented since they serve to illuminate the subsequent task of coping with the events and highlight some important clinical issues which require to be addressed.

Par: "I was, I admit a bit anxious, especially when I went away without asking questions, although when I calmed down, the doctors advice was clear enough.

Res: "Did you intend to ask questions ".

Par: "Well, you know how it is, such a big clinic and we were only in a few minutes. He (consultant) seemed so sure after seeing her, he just said I will put Linda on the waiting list and get rid of these troublesome tonsils". (girl, aged 5 years, control i)

Par: *"I knew it would be suggested, so I suppose I was half prepared, but it did not stop the awful feeling of panic. Once home I talked to a neighbour whose niece had it done and I felt a lot better.*

Res: *Did you think of talking about how you were feeling, say, going back to the clinic or phoning the ward?*

Par: *Not really, I went out there in a blind panic clutching her hand and found myself shaking looking for bus fares. (girl, aged 4 years control ii)*

The Initial Consultation - An important pre-coping phase.

Understanding the responses of parents requires a sensitive and knowing approach. The knowing is based on a knowledge of the clinic, its setting and the philosophy adopted when professionals are relating to families with a wide array of presenting physical ailments. The possible 'contaminating' effect of the researchers experience and familiarity with the setting and the role of those who operate within it, is addressed in this study by the constant reference made in this analysis to the need to stand back and 'listen to the voice of the text'.

A frequent observation made by the nurse (and communicated frequently to me) is that some parents expect the staff to identify their anxiety and provide supportive care in the absence of any indication from the parent that this is needed ("we are expected to read minds and on occasions are rebuked for offering support when none is required" - ward Sister during one of her visits to the clinic). The alternative argument is of course, that clinic counselling could potentially be an integral part of the proceedings and in that way be afforded a high profile, thus being explicitly available to all parents. If a parent is able or willing to convey her anxiety or uncertainty about an event to a staff member, concerted efforts are invariably made to identify that families particular needs, be it a practical problem, or an emotional need in relation to coming to terms with the child's treatment plan.

An important issue to emerge from interpretation of these data is that of parental control. Reference is also made by some parents to the sense of resignation they experience when faced with the news of hospitalisation and surgery. This small group perceive themselves to have had no control over the decision making process, indeed, few see it as a process at all, for example: "just had to accept the advice" or "resigned to the operation". For example, parents make reference to the obligation placed upon them to *accept* medical advice. The clinic consultation is, in this context looked upon as a time for unilateral decisions rather than a time for discussion of options.

The influence of perceived control on subsequent coping has been reviewed in the coping literature in terms of the relationship between active involvement in the events and a passive resignation to them. The parent assumes that control on behalf of her child in relation to the decision to accept or reject hospital treatment. Parents who are denied that choice experience a lack of control at the outset. This is confounded by uncertainty which includes the characteristics of ambiguity, lack of clarity and unpredictability. Incomplete explanations or failure of the parents to adequately understand the explanations given is a key feature of uncertainty in parental anxiety during children's medical treatments (Mishel, 1988). Fatigue and stress are instrumental in 'blocking' parents comprehension of medical explanations. This is exemplified in the comments made by parents who left the clinic suffering acute anxiety. Implicit in the comments made by this small group is the tacit assumption by the doctor that the information he gave was a) straight-forward and b) understood and accepted by the parent. Parents are more likely to distort information given to them or to form misconceptions when uncertainty is high (Maccoby and Martin, 1983). Re-appraisal within health care settings is optimally based on accurate information imparted by a staff member, or as a result of parent's subsequent experience. One parent was able to re-appraise the situation in the light of information from a well meaning neighbour. While accepting that some very effective 'counselling' takes place at an informal level between friends and neighbours, concern is expressed that this mother left the clinic totally unsupported and in a state of emotional upset. The genesis of anxiety in the mother is therefore identifiable at the earliest stage of the experience. The effect of this experience on the child is looked at in a later section.

Proponents of a reciprocal model of child parent anxiety assert that anxiety displayed by either child or parent contributes to that experienced by the other party, that is through emotion contagion (Eiser, 1986). In spite of the almost unanimous support for the anxiety reducing effects of accurate and supportive information being given to parents, it appears that the likelihood of parents obtaining an optimum level of information before admission is dependent on their ability to actively seek this information. This relates to the facilitative climate of the clinic consultation which the parents perceive to be operating at the time of the first contact, as well as the parents previous experience relating to professionals within the health care setting. In addition, parents ability to actively seek out information, is dependent on social class (McHaffie, 1988) as well as the personal qualities of the parent (Strachan, 1988). In addition the clinic milieu which includes the interpersonal qualities of the professionals who operate within it, is an important factor.

Discussion.

The relationship between linguistic process, cognitive activities and social structures is explored by Mehan (1983), within the context of professionals making decisions about learners. The mode of presentation of a communication made by professionals secures a high level of authority and status. Mehan describes a presentational mode which shares much common ground with the health care model, that is decisions are "presented, not discussed, credentialled, not negotiated" (p.96). The discourse of medical authority created by the professionals within the hospital communicates to the parents, this authoritative statement. This is important in inspiring confidence in the judgement and expertise of the professionals. Many factors operate to influence the 'success' of communications within the medical setting. In everyday discourse, meaning is said to be negotiated. Speakers and listeners both take responsibility for the construction of understanding. Mehan (1983) describes how listeners contribute to meaning in a discourse by making inferences from the conversational string. The listener is expected to communicate his understanding actively, or, alternatively request clarification, the purpose of which is to obtain more information and therefore minimise uncertainty and ambiguity.

The grounds for this negotiation of meaning are removed from the medical consultation by two key factors which operate at varying levels of intensity. The first is the institutional aura which envelops the hospital generally and the order and authority of the clinic setting in particular. Factors such as crowded waiting rooms, bustling ordered activity and endless waiting, serve to reinforce the institutional 'distance'. The second factor is the language used during the consultation. This is, in many instances, expected by parents to be variously incomprehensible or simply over technical (Hall, 1987). The effect of parents' expectations therefore may be to erect an imaginary barrier to communication at the outset. By the very nature of his status and position, the consultant or his registrar, is designated an authoritative figure. Many parents made reference to 'accepting advice' unquestioningly and some also went on to state that there was 'no point in going if you don't accept the advice'. The parents who remained uncertain after the consultation, or emerged from it feeling more confused, failed to enter into a discourse, they simply accepted the authority of medical opinion 'knowing best about the child's well being'. Parental expectations of the consultation influence the subsequent outcome of any discourse. For example, the expectation that the language used will be technical and beyond parental comprehension has been found to limit the number of questions subsequently asked by the parent whether or not her expectations were realised (Alderson, 1990). During my period

of clinic observation, prior to comencing this study, I was impressed by the *absence of technical language*. In addition, repetition formed the basis of any reassurance given. The few parents who did ask questions during my observation period, were treated individually and the questions were answered succinctly. While I was aware that some parents did leave the consultation appearing uncertain or uneasy, the doctor in charge simply reaffirmed his decision by saying that "...would go onto the waiting list and we would be in touch". During this pre-study phase only two parents were observed to question the medical decision. This was phrased thus: "You don't think she is too young do you?" Other questions relating to the practicalities of the event were asked, mainly in relation to the temporal nature of the proposed surgery. The comments made by the parents above, serve to highlight the parent's perception of the consultation as that of a traditional teacher/pupil relationship. The idea that a sharing of the decision making process can take place is not raised. The imbalance of information and communication is too great.

The mystery of the technical language and imbalance of information embedded in the hospital function serves to remove the grounds for negotiation of meaning in many instances. The speaker and listener *do not* share membership in a common language community (Mehan, 1983). It may be further argued that the parents do not have the expertise to issue such a challenge. The social class status of the family is an important variable. Higher social groups, expected to be more articulate, exposed to wider experiences, particularly in relating to professional groups, may feel more confident to interrupt, to question and to request clarification. The examples from the parents here suggests that the understanding gained is a passive one and not a cognitively active discourse associated with everyday language. Communication is however, a reciprocal process and each party has the responsibility to ensure clarity of understanding. Instead of signalling a lack of understanding by way of tacit and manifest devices, the parent remained silent, thereby tacitly contributing to the guise that understanding had been achieved.

As a preliminary to interpreting the responses of the parents to the child's admission to the ward, it is enlightening to present the overall findings from analysis of the question which probes the expectations of the parents' in relation to the events (qu. 7 and 8).

Reviewing the expectations of the respondents in relation to aspects of health care provision is important in shedding light on subsequent responses made to discrete elements of that experience.

The following responses were made by the parents on the pre-admission questionnaire and may also reflect the parents need to express their hopes of a standard of care for their

child which would be compatible with parental peace of mind. It is restated here that parents knew the responses made during all phases of data collection would not be shared with the staff responsible for caring for the child.

Previous parent participation studies have found an emphasis on parent 'doing for' and 'providing for' their hospitalised child (Coty and Ellerton, 1984). The mothers responses to questions 7 and 8 (appendix 3) were found to group into three specific categories.

i) Laying the Ground Rules. - Assertive parents

This group of parents (22) focused on the total parenting role and described aspects of physical care which they expected to be involved in; as well as the need for the parent to 'be there' to provide comfort and emotional support to the child at *all stages of the experience*. Definitive statements were made by mothers in this group in relation to the implicit value of the mother in the caring for her child within a strange environment. The general feeling to emerge from this set of responses is that of an assertive parent wishing to be reassured of her right to be involved, for example:

"I know my child better and I expect the nurses to ask me about aspects of his care"

"I expect to be totally involved in my child's care, after all I am his mother..."

"With the exception of medical care, I would expect to be completely involved and in charge of my own child"

Interpretation of the above comments signals the need of some parents to be in control, to accept responsibility for the care of the child during hospital treatments. This may also be interpreted as a pre-coping strategy of the parent in that she is attending to the need to remain in control of her own child, to be actively involved. Within the stress and coping paradigm, the relationship between perceived control, anxiety and subsequent coping with the stress may be teased out from subsequent comments made by this group.

A further pervasive interpretation may be that of the parent 'laying the ground rules' stating her own standard and criteria by which the experience will be evaluated by the mother. Within the context of the child health care system the parent, while coping with the unfamiliarity of the forthcoming event, is coping actively by a statement of expectations which may in fact mask an underlying uncertainty and perceived vulnerability. The nurturing and protective facet of the maternal role is seen to shine through interpretation of this groups' responses.

ii) Diffident and Uncertain

This group of mothers (19) stated that they did not know what to expect, some offered the

explanation of their uncertainty as 'not wishing to anticipate anything'. Many within this group made reference to the expectation of co-operating fully with the staff and doing whatever the staff felt was necessary. Other parents within this group made reference to the possible 'division of labour' during the child's in-hospital care, and gave some indication of the mother being 'best at reassurance.' for example,

"Well, we have to wait and see, I will be there...if I am needed"

"I expect the nurses to let me know how I can best help care for my child in this situation..."

"I am happy to do anything the staff ask me to, they are the experts..."

"They know how children act when going through all this...I will be there to help"

The above group appear diffident and uncertain and are unable to perceive their own role in the sense of 'mother as expert in the knowledge of her child' in this situation. This group therefore do not appear to expect to retain control over the events and it may be suggested that their diffidence and uncertainty place an added burden on the efficacy of the coping approaches subsequently adopted during the period of in-hospital care. It is important to point out however, that the above responses do constitute this group's approach to coping with the anticipated events. It is also relevant to state that while I went to considerable effort to reassure parent respondents that the information was entirely for the purpose of my research and would be kept absolutely confidential, some parents may have difficulty accepting that responses gained are not passed on to the staff. Although a speculative point it is worthy of consideration knowing the level of perceived vulnerability of parents, as they prepare to admit their child to hospital.

iii) *Defensively Hostile*

This final group (18) made specific reference to their fears in relation to being able to maintain some level of control over the events, for example:

"I expect to be in charge of my own child without being made to feel that I am a nuisance, or in the way"

"I expect to be around when she needs me most, and not be fobbed off when the staff want to do something to her"

"...to discuss care and to be kept informed and not to be asking for the information which I have a right to expect"

"I expect the nurses to see that this is a two way thing, I have a lot to do for my own son to make sure he is not upset by the goings on...the nurses have their job to do, but I don't expect them (the nurses) to see this as two separate things".

Discussion of Parents' Expectations

When asked what they expected from the ward staff during the time of their child's care, the responses suggested three distinct categories of parental expectations. The data give clear signals which suggest the categories adopted to describe the responses of the parents. The first was a firm statement of the right to continue the maternal role during the period of hospital treatment, this was expressed as a desire to be able to continue to do for the child, that which the parent would normally do at home, for example, read, help with care, be there and comfort the child. This group are seen to be 'laying the ground rules', negotiating the terms of the child's admission. An alternative interpretation may view this group of parents as vulnerable and uncertain and their firm statements of expectation may be seen to be an active coping strategy, that is 'I retain control over my child and I can cope', coping being contingent on the staff acceptance of the parent's competence and right to be in control of aspects of the child's care. Within the theoretical framework adopted for this study (Lazarus, 1984), the issue of perceived control is a central one in relation to coping with the events. Implicit in the responses from this group of mothers is the parents' right in relation to access to and involvement in the care of her hospitalised child. These rights are considered to be those of a partnership in care, which involves not only attention to the emotional needs of the child, but active participation in the planning and conduct of the physical aspects of care.

The second group of parents assumed a less certain approach and indicated their desire to 'help the nurse' to 'do whatever the nurses think would help the child'. Many parents within this group also indicated their intention to 'not interfere' or similarly, 'not to get in the way'. An indicator of passive acceptance of the primacy of the nurses' role over that of the parent is interpreted from the comments made by the parents in this group. It is however noteworthy that this group did, by and large, address the parental role and envisaged it being fulfilled in some 'token' way during the child's medical treatments. In relation to stress and coping theory, this group are seen to be expressing their anxiety and uncertainty within a novel environment. This is seen to be directly influenced by the absence of any real sense of control implicit in the statements made by this group of mothers.

The final group appeared to be preparing themselves for the 'fight to retain some control' and be involved in their child's care during his treatments. In effect, these parents were pushing against an open door, since the staff not only welcome, but actively encourage

parental involvement. Implications for clinical practice arise from the above interpretations. That is; the information sent out to parents requires to be made more explicit and inform parents *how* they can participate in their child's care, rather than the present 'wooly' statement which indicates that parents are welcome in the ward most of the time.

A correlation between the group of 'assertive' parents and the reports of extreme anxiety were sought. An direct relationship appeared to exist. That is; the parents who stated firmly what they expected and were at times almost hostile in their defence of the right to remain involved reported a higher incidence of extreme anxiety during the subsequent admission interview. Interpretation of this finding is met with a caveat. Defensive and at times aggressive behaviour is seen in parents of children admitted to hospital and is, on the whole a reflection of the parents need for reassurance, for counselling help and for confirmation of her unique contribution toward the care of her child. As a coping strategy, this form of parental behaviour is draining on the personal resources of the parent and on the time and the emotional resources of the staff. It is important to note that the experimental treatment had not taken place at the time of the above responses, therefore all groups were represented in all categories of response.

11:4 Phase 2 - The Preparation and Admission of the Child.

Coping with the reality of the 'here and now'

A question asked during a later part of the admission interview tapped the feelings of the parents about the child's admission at that time (Qu. 9).

The following responses indicate coping approaches by parents to the reality of the admission and surgery. The responses also introduce a further theme of parental anxiety, which was evident also in the parents reactions to the responses of the children (chapter 10). Some examples of the verbatim communications are presented, while maternal anxiety is the central theme teased out from interpretation of this set of responses, other emerging issues impinge on the genesis of that anxiety and contribute to an understanding of coping in context. This confirms the importance of looking to the analysis as a whole and not simply the illuminating but incomplete discrete elements, for example,

Par: "I am really anxious, stomach churning, I am much more upset than I thought I would be"

Res: "Can you put your finger on any particular anxiety?"

*Par: "Well it's just the thought of me leaving him before the anaesthetic and all..."
(Mum in tears at this point, counselling arranged with parent's consent)*

(girl, ages 4 yrs, 6 mths. control i)

Par: "Me! I'm a nervous wreck. It's impossible not to be up-tight. The nurses, they spend all this time trying to calm you down, I just can't take it."

(boy, aged 6 years, experimental group)

Par: "Oh yes, I am very apprehensive, I would rather have it myself than put her through it".

Res: "Has someone explained what is involved?"

Par: I have talked to the nurses, they are very comforting, but when it's your own...you know..." (girl, aged 4 years 6 mths. control i)

Par: I feel very mixed up, part of me says yes, she needs it before starting school. but the other half says she is too young, it is difficult being a parent and deciding things like this, you wonder if all the anxiety is worth it and if you wouldn't be as well putting up with the sore throats and the time away from nursery".

Res: "Would you like to talk to one of the doctors about your feelings?"

Par: Oh no! they have made the decision, she is on the list for tomorrow , that's it. (girl, aged 4 years, control ii)

Par: As a nurse I know I should feel calm about this but I am concerned. It is I think the feeling that I know all the things that could go wrong..."

(boy, aged 4 years, experimental group)

Par: "It's difficult to pin my feelings down, it is more a feeling of unease."

Res: "About anything in particular?"

Par: "That's just it, if I am honest I would have to say the anaesthetic and the operation on his throat -it all sounds very risky".

It is important to state here that all mothers, prior to my interview with them, had been seen by the nursing staff and had the opportunity to ask questions and receive information. Therefore the above responses are made following accurate and supportive information given to all groups. This is important because policies and practices which have been indicated to parents before, that is on the information leaflets sent out to the control groups and the information received by the treatment group during preparation, have been reinforced. Further examples of expressions of maternal anxiety at the point of the child's admission are presented since they introduce fresh insights:

Par: *"I am feeling very unhappy about it all. I am so nervous...jumping down everyones throat. It's good to sit here and talk though, it's just the thought of putting her through it, I feel like taking her home"*

Res: *"Would you like to talk to someone"*

Par: *No, I think it's just me I'll be fine when tomorrow is over" (girl, ages 3 yrs.6mths control i)*

Par: *"I am nervous about handing Phillipa over...you feel it is out of your control then"*

Res: *What is it that you are particularly concerned about?"*

Par: *Well you know...just not being there. I know anaesthetics are safe nowadays but you can't help worrying when you have decided to put your child through something like this, even if it is in her own good in the end" (girl, aged 3 yrs.6 mths).*

Similar concerns were expressed by mothers across groups. Many identified an anomaly in the philosophy of care within a Sick Children's hospital in relation to the policy of asking parents to leave their child before surgery. (47 similarly phrased responses); in addition, some parents (32) who reported feeling quite happy to be here and have the procedure done, also expressed disquiet when they realised they would not be with their child throughout the stressful process. for example:

Par: *"I am more nervous than Susy, I think it is just the thought of the operation itself, I can cope with anything as long as I can be with her. Yes I think I am very concerned about how she will be when I leave her, especially at the anaesthetic. This business of having to leave children before they go to the operation...She needs me here at this difficult time, it's what I came for, to be with and comfort her" (girl, aged 5 yrs. control ii).*

The responses of the two father respondents during this time emphasise the need to 'keep things low key' and express their confidence in the staff as well as in their child's ability to cope well with the experience. An important concern was raised by the father who was a single parent, that is the absence of effective support was identified as an additional coping task.

Discussion - Coping with the 'here and now'

As this analysis proceeds I find it necessary to step back a number of times to make sense of the statements that have been picked out. Since discourse is a coherent system of meanings, rather than fitting interpretations into a particular theme, the data here further inform and explicate the central theme of coping, but also raise other important issues to be addressed.

Issues of locus of control, perceived uncertainty and an awareness of the gravity of the proxy decision made all have important implications for the mobilisation of the coping resources of the parent.

It is evident that many (N=47) mothers perceive their absence at this crucial time to be likely to be interpreted by the child as abandonment at a time of heightened stress. The mothers own feelings of inadequacy, of feeling helpless in the knowledge of the power of the institution, presents an additional challenge to a parent already stressed by the admission and surgery of the child.

The situation outlined in the responses above, impinges upon parental personal control and subsequent management of the stress. The nature of a belief and the extent to which it is generalised determine its value as a resource or a liability in the appraisal and coping process. The external locus of control imposed on the parent by the authority of the institutional needs have clearly influenced the perceived control and subsequent coping responses of the parents who questioned the hospital policy. Studies on internal locus of control indicate that individuals cope more actively with the demands and engage in problem solving, particularly in relation to health behaviours (Lefcourt,1982). Conversely, individuals who perceive a situation to be outwith their control engage in emotion focused coping to a large extent. Every society has 'feeling rules', prescriptions and proscriptions about how people should feel and act in a particular social context (Hochschild,1979). Society then provides a kind of template of human relationships and meanings on which the appraisal of the significance of an encounter for ones well being depends. This is particularly evident in health care settings and is portrayed in the responses of the parents when they realise that their involvement in the care of their child will not extend to the identified maximum stress points. The effect then, is that it is not possible in this situation to stimulate positive appraisals of control.

The discourse explored above is seen to be folding around and reflecting on its own way of speaking, as theoretical insights help me to understand the inter-relationship between different discourses in this analysis. For example, the interpretation of manifest upset during the pre-admission period, (child responses p. 223) revealed many insights into the

parents expectations of their child and of the situation and also gave voice to the expressions of *parental* anxiety. Consideration of the possibility of the parents simply using the much resented hospital policy in relation to asking parents to leave the ward before surgery, may also be providing a focus, a sounding board for expression of the very real anxiety felt by the parents. It is not enough to look therefore only to one level of discourse but to seek out the common ground and address the contradictions between the parts and come to a richer understanding of the whole.

The issue of commitment to the proposed treatment plan is a further important area to address in the context of parental coping. The more deeply held the commitment, the more vulnerable the person is to threat, but, at the same time, the more motivated s/he is to ward off any threat to that commitment. The motivational property of commitment is an important coping resource because the person is impelled toward coping activity and is more likely to sustain it. Thus, the motivational quality of commitment has an effect similar to positive beliefs that generate hope (Lazarus, 1988). This interpretation has teased out the links between commitment and parental coping and parental anxiety which clearly influences that coping, in two main areas. The first is that of involvement in all aspects of the child's care and the right of 'being there', which has been sensitively articulated by many mothers above. Some mothers feel thwarted in the execution of the maternal role. The effects on the parent of her perceived 'failure' toward her child at a time of heightened need is an important issue to address, particularly in relation to parental coping and the parents's expectation of the child. The second area of commitment refers to the issue of proxy consent. This important area will also be addressed in relation to the subsequent coping by the parents.

Parker reminds us that discourse analysis entails at least two layers of objectification. The first is the layer of reality that the discourse refers to, that is, the child in hospital and parental anxiety about the effect and outcome. It is suggested that this is bidirectional, that is, parent concern about child and self in the situation. The second layer of reality is that of the dialogue, that is a reflection in the text on a discourse.

Thus this interpretation has teased out further important issues. Issues of locus of control, which strongly influence coping behaviour; perceived uncertainty; which is addressed in the child's responses in relation to parental uncertainty about the responses of the child; and in this interpretation, as uncertainty about the wisdom of the procedure being done at all. This in turn relates to issues of proxy consent and further influences the coping responses of the parent. Finally the issue of commitment is seen to impinge on locus of control, perceived uncertainty and especially proxy consent. There is then a coming

together, a fusion of horizons as all the issues are seen to influence the central theme of a parent coping with the impending surgical treatment of her child.

The Effect of the Experimental Intervention on Parents Coping

The 'here and now'

It is important to observe how the treatment group coped overall at the point of admission. The point has been made in the analysis of the quantitative data (9:6 and figure 4) that the level of parental anxiety across the groups was uniformly high and the experimental group were reportedly more anxious than the control groups. Reference to the quantitative data shows the experimental group to be more highly anxious in relation to specific individual items within the GHQ. Individual items which show a level of significance are included in the appendix. The most frequently made negative response was that of difficulty in coping in the pre-admission period, described as 'things getting on top' (appendix-table 10). Why then do the group who experienced more focused and individual preparation appear to be more highly stressed prior to their child's admission?

The literature addressed this finding in relation to the 'work of worrying' (Janis, 1984). One interpretation of this finding may be that the treatment group are working through their acceptance of the events and focusing on coping realistically with them. This finding is at variance with previous experimental studies, conducted mainly in North America, where the finding is of a uniformly beneficial effect of preparation to parents, although not often at the level of statistical significance. The relative dearth of studies conducted within the Health Service in Britain, renders comparative analysis difficult. The social and cultural differences are expected to influence at least in part, the findings. There are however, some key differences which may explain this apparent reversal of findings.

One important criterion to consider is the current emphasis on informed consent which involves the parent making choices on behalf of her child. These choices are optimally made with the maximum available information coupled with adequate professional support. The experimental group, while sharing some reservations about the initial clinic communication, went on to receive a great deal more information, individual counselling and support, during the experimental intervention. The finding of an increased report of anxiety within this group may suggest that the parents were actively coping with the reality of the events. They were able to express their anxiety and to begin to work through the process of coping with the stress inherent in their decision to seek surgical treatment for their child. All 30 parents within this treatment group expressed an indication of the positive benefit to them and to their child of the pre-admission preparation.

I would now suggest that, in the light of the incidence and intensity of maternal anxiety reported by the mothers, that it is in fact unrealistic to expect any form of preparation to completely allay the anxiety experienced by a parent as s/he prepares the child for surgery. What can be achieved however, is a situation where parents are better informed and can prepare their child realistically for the forthcoming events, and where the parent can begin to work through the process of acceptance of the treatment per se. The nurse is clearly in an optimum position to become more involved in effective pre-admission care. In the context of planned admission for ENT treatments, as reported by the mothers in this sample, such support and care appears to be afforded low priority. It is a salutary reminder that the initial clinic consultation is in fact simply the first stage of the process of decision making (Alderson, 1990). Whether that decision making is related to momentous major surgery or to more 'routine' procedures is, to the parents irrelevant. The value of the intervention may therefore, also be seen as a continuation of the process of adjustment to the planned treatments.

The responses of the experimental and control groups to the same situation are interpreted as qualitatively different. While the treatment group certainly express a higher level of anxiety, and relate the cessation of this anxiety to the successful outcome of surgery, this anxiety has been channelled and controlled, focused on the child and his experiences. The responses from the control groups suggest that this group's anxiety was not tightly focused on the stressful events but pervaded every aspect of the mother's life prior to admission:

*"I crashed the car the other day, I have been really up-tight" or,
"I have been falling out with my neighbours, it's me really, just very anxious".*

In some instances the reported anxiety was out of control in that it affected relationships with family and friends and impinged on maternal physical and emotional health. Mothers in the control groups appeared less able to manage their anxiety. Coping as a dynamic and constantly evolving process is viewed in this instance, to be static and unmanaged. Mindful of the added stress to which the control groups are exposed, that is being in the ward and experiencing the hospital 'aura' for the first time, it may be the case that this group were expressing the earlier stages of the coping response, that is, overt anxiety. While it must be accepted that the responses of the control groups are confounded by the unfamiliarity of the hospital milieu; and more specifically by the demands placed upon the parents by the detail of the child's admission, that is being seen by the admitting nurse and later, the house surgeon, the qualitative differences between the expressed anxiety of the control group and that of the treatment group raise important points in relation to the positive effect of the intervention on subsequent parental coping.

When a more focused question was asked, outwith the GHQ-12, for example, "how do you feel now" (Qu 9) interpretation located the parents anxiety in time and event. This was important since the pre-admission preparation and general concerns may have exaggerated the incidence of parental anxiety reported. This question therefore asks the parent to stand back, aside from the past few days - and state how they felt now. The majority (70%) of the sample indicated an array of physical and emotional 'symptoms' ranging from headache, stomach upset, to feeling anxious and on a few occasions 'panicky'. One example will be presented since it encapsulates the extreme responses:

Par: "I feel anxious and don't know how I am going to get through the next few days"

Res: "Would it help to share your concerns?"

Par: "Well you know...(mother in tears at this point)...I keep thinking that something will go wrong...you know, during the operation..."

Res: "Would you permit me to ask Dr. or Sister to have a chat with you?"

Par: "Oh no!, don't bother them again, they have all been so good, no I am happy just to sit here and chat with you"

(girl, aged 4 yrs, 6 mths. experimental group)

This interview was cut short when the child returned from the playroom. I did not wish the child to see her mother's distress so some time was spent with the family talking lightly about general topics. I then left the child and mother alone. Twenty minutes later I returned to the mother and asked her if she would like to have a word with Sister who was now free, she readily agreed.

Discussion of parent's feelings at the time of the child's admission

Generally parents who scored higher on the GHQ also expressed anxiety and explained its origin during the admission interview. Recurring issues include those identified in relation to the earlier interpretation of parent's acceptance of the need for surgery. These include anxiety related to the objective stress, that is the child undergoing surgical treatments which necessitated anaesthesia. Interpretation of the many responses leads to the understanding that there is a necessary inter-relationship between the perceived uncertainty expressed by the parent (that is, in relation to the child's coping during the events, as well as uncertainty about the outcome of the procedure), and the perceived control parents have over the events. The issue of consent and involvement in the decision making process are central factors of influence in the uncertainty and lack of control

experienced by parents. This is evident when across group analysis was undertaken. That is, although the experimental group still reported a high level of anxiety, the anxiety was focused on specific aspects of the experience, for example, the surgery and the implications of parental absence during maximum stress points. The control groups however, identified uncertainty in relation to the necessity of the procedure, even after the child's admission (42/60).

Lazarus (1982), reports that cognitive appraisal of meaning and significance underlies and is an integral feature of all emotional states. He further purports that emotion is never totally independent of cognition. The mothers who had not received particular preparation for the events are therefore viewed to interpret personal meaning based on inadequate information, (that is the information presented during the first stage of the process of acceptance of surgical treatment) and more importantly, on lack of appropriate professional support. Since no opportunity for reappraisal was presented to this group, some entered the hospital situation in a state of high tension.

Cross reference with the pre-admission coping reported by the control groups suggests that some parents perceived themselves to be coping well prior to the event, but found the reality of the 'here and now' extremely worrying. In relation to coping theory, it may be postulated that these parents were not engaged in the 'work of worrying' prior to the child's admission and therefore, when faced with the threat of the event itself were overwhelmed with feelings of crippling anxiety and on occasions panic (7 reports). The relation between emotion and cognition is apparent as we see parents who report that they are happy to accept the procedure for their child, are relieved to have the problem dealt with, and are cognitively active in coping with the situation. The reality of the event triggers an outpouring of parental feelings of anxiety and concerns which they have not hitherto addressed. The possibility therefore of avoidant coping occurring simultaneously in parents who are cognitively active and engaged in problem solving is raised by this interpretation. Concern with individual differences leads inevitably to concern with personal meaning and to the factors which shape such meaning. We actively select and shape experience and to some degree mould it to our own requirements. As individual case analysis here has shown, the richness of the individual responses defies simplistic reduction. A final laconic comment in this section which speaks volumes to me about the reality of parental anxiety in this situation is quoted verbatim:

Par: "It wid be a giy queer mither whay said she wisna bothered about a' this - whit dae ye think lass?"

While a philosophical acceptance of a degree of anxiety may encourage or signal realistic coping, concern is expressed about the extent of extreme anxiety experienced by some parents. Addressing this finding and interpreting the illuminating responses, I am of the view that the extreme level of anxiety *is* preventable in many instances. While the point has been made that preparation programmes may not allay anxiety, they should be able to mitigate the intensity of that anxiety. Rather than look solely within the mother (neither of the father respondents showed extreme anxiety) for an explanation, it is important also to address the interface between mother and child in the context of the hospital environment and also, to look at the effect of the hospital milieu on maternal perception of control, uncertainty and perceived threat as these factors impinge on parental coping. Central to discourse analysis is the need to engage in a process of exploring the connotations, allusions and implications which the text evoke. These implications are related directly to the manner in which the organisation of the ward functions.

The issue of maternal competence within the ward environment describes the degree of 'fit' between the parents' expectations of self in relation to her role in caring for her child and the actual level of satisfaction felt by the mother in carrying out this role. The level of competence in turn is seen to relate directly to the degree of control the parent is perceived as having over the events. In addition, the perceived expectations of the staff in relation to the maternal role may be instrumental in shaping the parents expectations of self in the situation. It may be the case that the very professional expertise and structured routines of the ward staff challenge maternal competence at a time when most mothers 'need to be needed'. In this respect the mother requires confirmation of the uniqueness of her role in caring for her child. In addition, the protective aspect of the nurturing role may be seen to be thwarted, particularly if the mother remains equivocal in relation to the issue of proxy consent.

The final point in relation to interpretation of the parents feelings at the time of admission requires repeated reference to the practice of asking parents to leave prior to surgery. As a recurring theme throughout the data, it is important to review this issue within context. At the point of the child's admission some mothers conveyed to me a feeling of helplessness, of their inability to influence the events at the time when the parent expected the child to be more highly stressed. This clearly increased the level of uncertainty and contributed to the feelings of anxiety, which in turn influenced mobilisation of the coping resources of the parent.

One example of this point only is cited, again it represents an extreme but is justified in the

One example of this point only is cited, again it represents an extreme but is justified in the light of the meaning of the event for this mother:

*Par: "My past experience makes it impossible for me to see this calmly, I know it is necessary, but I do feel so very troubled today. I can't help but wonder whether I am doing him harm, he is bound to sense all this anxiety, and I can't even be with him before he is taken away to the theatre. I think if I had known things were going to be so difficult I would not have gone through with it. If I turn back now, my son will for ever be afraid of hospitals."
(boy aged 6 years-father died during surgery).*

Mindful of Parker's plea that interpretation of data must make sound theoretical sense, rather than artificially merging one theory with another, the data interpreted here seek expression in a range of theories, which then come together within the conceptual framework of stress and coping.

The absence of appropriate support for the mother quoted above is evident. It may be the case that this mother did not address her own responses to the admission of her child prior to admission, but rather focused on the preparation of the child. It may also be the case that the support network available to this mother was that of the extended family, who were still in the process of grieving the loss of a loved one. In fact the staff were sensitive to this mother's needs and gave every possible support throughout the process of the in-hospital care. The fact that this mother and child were not in the experimental treatment group, meant that pre-admission support was sadly lacking. Interpretation of the above response, while accepting the extreme mitigating circumstances, adds support to the findings presented earlier, that is the control groups had difficulty accepting the need for surgery, particularly at the point of admission. This may tentatively be explained as being due to the lack of support in the decision making process and by implication, the parent's had not in fact worked through the issue of proxy consent. This little boy progressed through an uneventful recovery and his mother used the post-hospital questionnaire as a vehicle to convey her feelings of dissatisfaction about preparation and aspects of subsequent care .

The issue of support is an important one and one not confined to the extreme example given. The reality of single parent families is apparent in this study. Twenty four families were either divorced or in the process of separation. Eight mothers raised the issue of support. Individual case analysis leads to the realisation of the need for support in a higher number of the sample, an example of the feelings expressed is given:

Par: "...Being on your own you tend to keep it to yourself, you know there is a limit to

how much you can tell a friend, It feels good to be here and be able to talk ".

The presence of support is identified as an important coping aid, this appears to be more effective when followed up by professionals, for example, during the experimental intervention. The absence of such support is seen to place a greater obligation on the nursing staff to counsel individual families and help them to cope adaptively with the stress of their child's admission.

Before turning to interpretation of the data which explores parental satisfaction, it is of moment to refer back to the analysis of the children's responses and to tease out the relationship between the mother's anxiety and the children's distress. In addition, the influence of preparation on these variables will be reviewed.

The relationship between Maternal Anxiety and Children's Manifest Upset.

The effect of emotion contagion was looked at across the groups, particularly in relation to the reports of maternal anxiety discussed above and the reports of upset in the child before and during hospital treatments. Parent's responses to their child's distress are important aspects of parenting, particularly in relation to children's competencies. However, is it necessarily the case that a highly anxious mother will convey that anxiety to her child and further, will the child's subsequent adjustment reflect that emotion contagion?

The children who were prepared within the experimental treatment group were perceived by the parent to be less anxious and to show fewer changes in behaviour prior to admission than was the case with the second control group. Reference to the quantitative analysis shows no significance across groups on the summary variables which relate to children's distress throughout the experience, although interesting distributions are found. Reference to table 5 (9:6 iii) shows the child's in-hospital adjustment to be 'better' in the second control group, this is a reversal of the findings of pre-admission coping. It has already been discussed in the earlier analysis that the better adjustment of the second control group during the in-hospital treatments may be partly due to the additional attention given to this group on admission and may thus be interpreted as being indicative of emotion focused coping. Attention to single case analysis tends to support this interpretation in that some parents within the second control group did indicate their satisfaction with being given 'such individual attention' when the child was admitted. Conversely, single case analysis also signals the very high anxiety experienced by parents within the second control as well as the other groups. The attention given to control group two was clearly not enough to mitigate the anxiety felt by the parents, although the

children appeared to have benefited from it.

The in-hospital adjustment of the experimental group highlights some clinically important findings. That is; although the second control group scored 'better' on the measures used, individual case analysis drew attention to the better adjustment of the experimental group during crucial maximum stress points. This has been discussed in the previous section and is raised here to explore the relationship (if any) between the better adjustment of the child during these stress points and maternal anxiety about the child's ability to cope with them. Most of the mothers in the experimental group, while accepting the nature of the objective stress, that is anaesthetic induction and surgery, were able to focus their anxiety on the successful outcome of these procedures and did not project the anxiety onto their uncertainty about the child's responses to the stress. There appears therefore to be no clear relationship between maternal anxiety and subsequent child coping within the experimental group in relation to the maximum stress points of the experience.

The home adjustment summary variable (table 5 vi) shows an interesting distribution. That is; the children within the experimental treatment group fared better than the children within the other two groups. Analysis of children's responses in the preceding section (10:5) give voice to the varied adjustment of the children within the treatment group. Parents' perceptions of how the child coped overall with the experience suggest a correlation between parents' expectation of change and change subsequently reported (appendix tables 14,16).

Interpretation of the findings from both child and parent responses leads to an understanding of the wide variability in responses. No clear consistent relationship was found between maternal anxiety and children's distress either during or following hospital treatment in the experimental group. However, some association was found between levels of expressed anxiety in the mother and manifest upset in both control groups. A more important clinical finding however, is the *absence* of distress in some children (within all three groups, but particularly in the experimental group), whose mothers reported extreme anxiety. This finding is an important one and suggests the operation of protective mechanisms as well as the absence of emotion contagion. It is therefore important to reiterate that, of the mothers who described extreme anxiety (see verbatim comments) their children, on the whole did not reflect this anxiety either during or following admission. For example, the data presents instances of parents who were visibly very upset at the point of the child's admission and were considered by the researcher to require counselling help from a member of the nursing or medical staff. The children of these parents were either mildly upset during the maximum stress points, or went on to cope

uneventfully with the events of admission and surgery.

Summary

Parents Feelings about the Child's Admission

Interpretation is a response to questions put, not solely by the interpreting subject to an object (the text). It is a response to questions raised by the subject matter of the text (Llewelyn 1985, p 115).

Coping with the admission for surgical treatments in the child brought forth a very wide range of parental concerns and frank anxieties. Interpretation of this data has led to the understanding of coping being contingent upon the acceptance of the procedures per se, that is the parents' level of commitment to the necessity for surgery, as well as fulfilment of the maternal role in the situation. This in turn addressed the perceived degree of control the parent could expect, over the events, in addition to the recognition of maternal competence to exercise that control. The successful outcome of the procedures as well as the child's responses to them were identified as primary concerns.

In using the parts to create a meaningful picture of the whole unifying concepts are identified, for example, the relationship between coping and perceived control, between commitment to the procedures and control over the events and also to the inter-relationship between the perceived uncertainty expressed by some mothers and the approach to coping subsequently mobilised. Many of the occurrences of anxiety suggested a deeply felt uncertainty. This uncertainty was found to span the entire process from pre-admission coping to concerns during the in-hospital period and found expression mainly in concerns relating to discrete elements of the process, for example, anaesthetic induction. Mindful of Billig's et al (1988, p. 23) assertions that 'discourse can contain its own negations which are part of the implicit rather than the explicit meanings'. The implications for understanding parent's coping in this situation are important. While the presence of parental anxiety prior to a child's surgery is anticipated by most paediatric nurses, the intensity of that anxiety is considered by many to extend beyond that expected within the context of the procedures to be performed. It is appropriate to quote the response made by Bergman two decades ago (1975)

The reason for the child's admission may be immaterial. Understanding the level of parental anxiety requires attention to more than the reason for the hospitalisation, it requires appreciation of past experiences, present needs and future hopes...While there may be a qualitative difference in the illness requiring treatment, these differences are ones of degree rather than kind...
(p. 142)

What is important is the presence of uncertainty. While the nature of the stress may be qualitatively different for many parents, for example those whose children undergo open heart surgery, coping with uncertainty about the decision to accept treatment, coupled with the natural anxieties about the outcome serve to exaggerate the stress inherent in the situation.

Attention now turns to the final section to be addressed in this analysis, that is the satisfaction felt by parents with the process of their child's admission. This, in keeping with the analysis to date requires to be reviewed in a temporal light. Retrospective accounts of satisfaction, while tinged with factors which influence the personal meaning of the events for each parent, that is events which relate to the outcome, for example, maternal tiredness, child recovery and the effect of the sense of relief felt by parents to have their child safely home are interpreted here to further inform an understanding of the influence of the experimental treatment.

Reference has been made to the difficulty inherent in and the methodological problems which attend, studies of satisfaction with health care (Street, 1992). These problems relate to the ambiguity of many satisfaction indices developed and the difficulty of ensuring that the client's response is an accurate indication of satisfaction. Clearly, many situation and person factors operate to influence this dichotomy. One interpretation of satisfaction holds that the object of investigation is to tap an assumed set of attitudes held by the respondent in relation to such matters as the approach of doctors to patients, or to the quality of care received (Jones et al,1987). The assumption of such research is that people adopt relatively stable views in the form of attitudes which can be identified by the researcher. This sense of satisfaction shades into slightly different use to which the concept is sometimes put-to identify respondents views of the value of particular consultations or stays in hospital, to specific health problems experienced by the respondents. Attitudes in general may be quite distinct from and independent of evaluations of the benefit of specific discrete health care received.

This study employs pre-admission expectations criteria as well as satisfaction as an outcome variable. Cross reference between the two temporally distinct variables will provide support for the validation of the approach to satisfaction studied. It is also important to emphasise that, in this study the parents respond on behalf of their child. Satisfaction is therefore an indirect measure of the quality of child care from the patient's perspective but a direct evaluation of parental satisfaction with this care. A further

aspect of the satisfaction data which increases the validity of the approach is that of the number of respondents who actively expressed areas in which they felt satisfied or conversely unhappy with. One factor which has plagued researchers in this field is the obvious problem of whether respondents answers to questions correspond to their real views. There may be strong pressure on respondents to express socially acceptable views when talking about health care. French (1981) reports from her study of patients undergoing surgery that she experienced a 'perceptible frosting of the atmosphere' when she asked patients for their views about treatment (p.27). While it is observed in practice and in this present study that respondents on the whole, wish to avoid making personal criticisms of the staff, particularly the nurses (10:5), it has also been found by other investigators that the respondent is more likely to make candid responses outwith the immediate health care setting, in the privacy of his or her own home (Fitzpatrick 1990). An awareness of the presence of such factors as the 'politeness virus' (Donan, 1990) and the effect of the possibility of subsequent contact with health care, for example in follow-up appointments in tailoring the responses of parents is an important consideration.

This section will address satisfaction with the pre-admission care, in-hospital treatments and preparation for home. An overview of the emerging categories will be presented prior to turning to an interpretive analysis of across and between group satisfaction.

The first issue to arise is that of a distinction between the system and the people who operate within it:

11: 5 Phase 3: Parent's Perceptions of the Process of Hospitalisation of their Child

i) Satisfaction with Pre-Admission Care.

The People and the System

A general feeling of satisfaction with the people involved in preparing families for the experience was made while vociferous comments about the deficits within the 'system' were identified. Nurses were unanimously perceived in a positive light, and this presents a paradox since few parents outwith the experimental treatment group actually had direct contact with a nurse prior to admission. The ward sister, or her senior staff nurse were in attendance at the outpatient clinic, on few occasions during the period of the study. An example of the commonly cited written responses is given: (17 similar responses)

"It's terrible really, all that waiting on a list before your child gets his much needed treatment. The staff do their best but they can't work miracles.

The pressure on the waiting list was considered a factor in this group's expression of dissatisfaction. The 'routine' waiting period may be 6 - 9 months. It is important however, to point out that a child who is having serious problems and whose general health is impaired by the chronicity of the ENT problem, is generally placed on the priority list and may be admitted within a few weeks.

An alternative interpretation of this waiting period was made by two mothers, both of whom were primary school teachers:

"...It was really very well planned, they waited until the school holidays before sending for him, it would have been very awkward during term time"

Direct concerns about the nature of the preparation also emerged.

Preparation - an 'ad hoc' activity

Many mothers made reference to the limitations of the preparation given during the out-patient consultation, as well as to the 'barely adequate' information contained within the preparation leaflets (these leaflets were re-written shortly after discussion of the findings with the ward staff). Comments from mothers in all three groups suggest a general feeling of dissatisfaction with aspects of the clinic consultation, while preparation was the main factor identified, this was interpreted to envelope other key issues of communication. Some mothers within the treatment group made the point that they would have been very unhappy about the preparation given if the clinic had been the only source of that preparation.

Reference has been made to the direct expressions of disquiet expressed by mothers during the admission interview regarding the clinic agenda. It is relevant in this section to present the feelings of the mothers as they retrospectively reviewed the experience. Interpretation of this data leads to an understanding of the perceptions held by mothers of purpose and function of the clinic consultation. In addition, the attitudes of the staff who operate the clinics suggests clear preconceptions of the patient's role in the consultation. A representative sample of responses is now presented: (34 comments, all negatively phrased).

"I had all my questions ready but they went out of my head as soon as we went in. The consultant was very nice, he told me what should be done and I didn't really think it was expected for me to ask questions" (my emphasis)

"They made me feel it was all routine, which I suppose in some ways is reassuring, keep it all very low key. I felt hassled though and felt I couldn't relax and

ask questions"

"Thinking back, I am so relieved that we had the chance to come in before the op. The clinic was fine, but there was little chance to sort out your worries, let alone ask about them"

"You hear so much about the health service just now, all I wanted was to know I was making the right decision for my son. It wouldn't have taken much to have had a chat with someone who knew. Instead I was left feeling that it was only a small operation, he should have it and that was that. I felt really uneasy when I left the clinic."

Discussion

The above small sample of responses, coupled with reference to the discussions in the earlier section of this interpretation serves to highlight the absence of attention to the psychosocial issues which accompany proxy consent. After receiving and thinking about the evidence and reaching a conclusion, parents need to become committed and want the chosen decision. This voluntary consent in the child's interests is sensed rather than observed. It is now my contention on the basis of this study, that it also influences parental anxiety throughout the process and ultimately, satisfaction with that process. The decision to accept surgical treatment for the child is based, not necessarily on what parents want for themselves, but on what they believe to be in the best interests of the child.

The objective approach to consent values detachment. It separates the observer from the object of study (Keller, 1985). This objective approach also plays down feeling and value judgements and measures 'truth' by its distance from subjectivity. The alternative approach is to become fully absorbed in the decision making process and through thinking, feeling and intuition being intensely aware of the whole. An optimum balance is possible, that is the opportunity for parents to rationalise the advice in terms of their understandings of the procedures, implications and outcomes. Clearly, the clinic consultation alone cannot meet this goal. Time for adjustment, to work out what is, for each parent a necessary question and to facilitate reappraisal are all part of the continuum of proxy consent. It is apparent from interpretation of the qualitative data in this study that a majority of parents made a passive decision. There was, therefore, apart from the experimental treatment group, no opportunity for coping to reflect a growing awareness of the voluntary nature of consent. Voluntariness in the context of proxy consent is elusive, subtle and complex. It requires trust in information, the informer and the context. Above

all it requires commitment on the part of the staff to ensure a facilitative and enabling atmosphere in which that trust can develop. It requires to be repeated that the clinic consultation represents the first stage in the decision making process and attention to the support parents require throughout that process is not addressed by the existing system.

The Preparation Leaflet A Token Preparation?

Many parents went on to express concern about the ambiguity and inadequacy of the information leaflet which represented the only preparation given to the (60) control group families. (39 similarly phrased comments) for example:

"The booklet was helpful about what to bring in, visiting and so on, but it would have been better if they could have said definitely that you could visit the ward on such and such a day, rather than leave the Mum to 'phone up and make the arrangements with the ward"

"They said on the booklet ring up and make an appointment to come and see the ward, but you dont like bothering them, they are always so busy and short staffed"

"The wee booklet was fine for the essentials, what to bring in, when to visit...and handy for the numbers of the buses. It did say that a child needs his mother and family, but the ward said when we arived that sisters couldn't really visit and certainly not on the day of the operation. What is a mother to do when there is no-one else at home to collect the bairns from the school?"

It is interesting to note that the comments above, while largely made by the control groups, were also reported by some parents in the experimental group. The treatment group's responses suggested that they compared the efficacy of the leaflets with the impact of the experimental intervention. The key message which arose from this comparison was that of dissatisfaction with the purely factual 'list' of things to do before and during the child's admission, compared with the "caring, informative and reassuring" nature of the experimental preparation.

Many factors influence the parents willingness to take the initiative and contact the hospital ward for clarification or further advice before admission. Of these factors, previous experience of health care and its influence on shaping present expectations is important. Closer analysis of this sample shows some interesting findings.

A relationship between social class and parents readinesss to arrange a pre-admission visit was found. The majority of the 39 parents who commented that they did not want to

"bother the staff" were in social class 3/4 (26 parents). Mothers in other social groups felt that any other issues they wished to discuss could be dealt with on the day of admission. Implicit in this response is the presence of the need for further information, counselling or simply reassurance. A few mothers also commented that the "preparation visit should be available to all families". It is recalled that this question was answered retrospectively, therefore parents had the opportunity to talk to other families while they were in the ward. This clearly included some influence from communication with the experimental group. The above comments from mothers suggest that the rules governing how the ward functions are inflexible and incompatible with the individual perspective. A clear example is the mother who had problems arranging alternative care for her daughters at home to enable her to enjoy peace of mind during the time spent with the child in the ward. From the staff point of view it has to be stated that had this problem been exposed, every attempt would have been made to find a solution. The staff are indeed, at an individual level very flexible in their approach to the needs of the family. The factors which operated to prevent this mother from coming forward and seeking advice are thought to reside within the mother as well as within the 'system'.

A positive statement about the manner of preparation was made by 6 mothers, for example:

"I like the way they (the staff) stepped aside and let me prepare my child in my own way"

This small group of mothers highlights some important differences in attitude toward preparation across the social groups. All 6 mothers were economically active, professional women who stated what they expected from the experience. Cross reference was made between this groups responses to this question and comments made in relation to an earlier question which asked about the parents feelings when doctor first suggested surgery. Without exception, this small group stated that they were happy to have the problem dealt with. However, continuing individual case and item analysis proved illuminating for this group. All mothers expressed a high level of pre-admission anxiety in spite of their apparent control. In addition 4/6 had considerable difficulty accepting ward policy in relation to parental absence during maximum stress points. The age of the child was not a factor in their responses. Attention is now given to the effect of the experimental intervention on parents expression of satisfaction with pre-admission care.

The Effect of the Experimental Treatment.

i) Satisfaction with Pre-Admission Care.

It will be recalled that 27 of the 30 parents in the treatment group perceived the effect of pre-admission preparation for their child to be beneficial at the time of the intervention (p.224). All 30 respondents within this group reported that in retrospect, the preparation had been most important. Each respondent gave several comments to support their view. Categories of responses are grouped and emerging themes are developed from the examples given as follows.

a) Preparation based on concrete reality rather than abstract imaginings (for example:)

"...This was an excellent idea, he still asked awkward questions, but I could answer them truthfully and talk about what seemed to worry him"

"It was so good being able to come in like that. I could never have thought of telling him all these things. We had no idea it would be so welcoming. I felt I could ask the nurses anything and they did not make me feel like a silly mum".

"I was most impressed by the time they gave you, you felt you counted, that it was not just the child going through this but the parent as well. I was able to carry on with his preparation at home knowing I was telling him the right things".

"The visit before helped me a great deal. I felt more relaxed. My daughter was really helped by it, books are fine enough but she was definitely better for seeing it as it is".

The effect of media 'preparation' was also suggested by 10 parents, for example:

"He was really 'up-tight' before the visit, watching his programme (Children's Ward, Children's ITV) made him really panic, he couldn't understand that all these things didn't happen to every child who went into hospital. The nurses were great, they took time to explain what would really happen when he went in, it was a super idea!"

While it is beyond the scope of this analysis to discuss the standard, content and accuracy of such children's programmes, the potential for harm or benefit does I believe have to be addressed by the professionals. This view is supported by the literature, which indicates that inappropriate 'preparation' may encourage fears and fantasies based on immature imaginings (Poster, 1983).

Developmental considerations serve to remind us of the misconceptions and frank inaccuracies of some children's perceptions of hospital and medical treatments (chapter 3). Concern about preparing children across the 3-7 years age range was felt by me at the early stage of planning the intervention. The measures taken to address this issue are described in chapter 6.

The three children who did not appear to benefit in the short term from the preparation initiative have been studied in relation to their subsequent coping (p 10:8 and 10:10). In addition, the parents of these three children had this to say after transfer home: sample of combined comments-

I feel sure now having been through it all that s/he did benefit from the preparation. I saw other children in the ward who did not feel at ease and were obviously frightened by what they saw... At least my child knew what was going on, I felt the trust was there... I always feel children have the right to know what is happening to them...A good idea for both of us"

b) Familiarity with and Confidence in the staff

Mothers (10) also commented on the importance of the ward atmosphere, the friendliness and approachability of the staff and the value of child and parent being familiar with the hospital milieu prior to admission. Two examples encapsulate this theme:

"My child felt really at ease, she was very pleased with the way the nurses talked to her and made her feel special. The playroom, showing her her own bed and making a big thing of her went down very well, she was looking forward to coming in.

"The nurses understood the anxieties of my son (and mine) they explained everything so well. You felt comfortable somehow, there was no distance between us and the staff"

The use of the term distance is a most insightful one in the above context. It suggests an initial expectation of finding a professional barrier and satisfaction that none was found.

The value of parents and child being able to sense the atmosphere of the ward before admission is clearly expressed in the above comments.

c) Child and Parent - an Individual Approach to Preparation.

Many of the respondents within the treatment group also went on to comment on the effect of being 'treated as individuals' (16 variously phrased comments). Two responses are quoted to convey the essence of these feelings:

"The chance to talk to the staff in private made me feel we really mattered, they were interested in us".

I was most impressed by the way the staff cared. You felt they were almost expecting us as guests, they were so welcoming".

The effect of the experimental treatment is perceived by the parents to have been positive. All parents stated that they and their child benefited in specific ways from the initial contact. Mindful of the comments made by some families in the control groups about the absence of pre-admission preparation, this analysis points to the implicit value of extending this facility. This is a subject for discussion in the final chapter.

The final section interprets the responses in relation to satisfaction expressed by the parents with the care while the child was in the ward.

ii) Satisfaction during the period of In-Hospital Care.

Since the majority view expressed by the parents was one of satisfaction with the care received during the child's treatments, a limited selection of responses will be presented to give the full flavour of the satisfaction expressed. 65 of the 90 respondents reported feeling either very satisfied, or satisfied with the care during hospital stay. It is important to state here that within this majority group, some respondents, while expressing overall satisfaction and describing the areas they felt happy with, also went on to elicit further aspects of care they felt quite unhappy about, that is 32 of the 65 also made constructive negative comments.

Throughout the process of interpretation, the horizon of understanding is tested and reformed through the process of dialogue with the text. As part of this process, I am constantly making comparisons amongst instances in the text (cf. Glaser and Strauss, 1968, Glaser, 1972) and amongst the evolving themes and their interplay with the text.

The remaining 25 respondents either ticked the 'dissatisfied' response and went on to

explain why they felt unhappy about the care received (19) or simply ticked the response and made no further comment. However, the six mothers in this latter category did go onto respond to the final question (qu.21- appendix 4) and made some direct comments about their feelings of dissatisfaction with preparation and level of involvement in the child's care.

Reasons stated for satisfaction.

All (N=30) respondents within the experimental treatment group are represented within this satisfied category. Some areas of satisfaction are now presented and discussed. The following representative sample of comments from the 65 respondents who expressed satisfaction are abbreviated when overlapping issues are observed.

a) *Meting Emotional Needs*

"I... felt comfortable with the staff"

"I could trust their judgement, they seemed to know us well..."

"The nurses were always there, ...you never felt you were coping alone"

"I was in charge of my own child...yet the staff were there if you needed them"

"The nurses found the time..."

"I... felt completely at ease"

"I enjoyed the calm and patient atmosphere-the nurses had time for the children..."

"You felt the nurses cared and would just sit and cuddle an unhappy child"

The above responses attest to the very high standard of nursing care delivered. It is evident from analysis of the above comments that the nursing staff were very familiar with the emotional needs of the mother and child and were able to meet those needs most of the time.

b) *Perceptions of Normality achieved during Institutional Care*

Many parents made some reference to the general ethos of the ward and to the lack of a crises oriented approach to caring achieved by the nursing staff. These comments are teased out from amidst the range of themes addressed by some mothers as they wrote an account of (sometimes at great length) their opinions about the care received.

"I was amazed and delighted at how 'normal' the nurses made everything seem, the children had their routine and yet the atmosphere was very homely"

"If you didn't know how busy it was and see all the children demanding all that attention, you would never realise just how organised and calm the staff were"

"Children vomiting blood, young kids screaming for Mum, doctors appearing looking for the ward sister, telephones ringing and a group of children waiting to be admitted...and yet it was all very calm and unflustered..the nurses kept their cool and were always very pleasant"

c) Parental Role fulfilled

A proportion of the mothers (16/30) also commented on the fact that the nurses were able to stand back, accept the primacy of the parental role and on some occasions ask parents' advice about the care of the child, for example:

*"Parents in the ward were made to feel necessary, and never intruding"
I like the way the nursing staff asked me about my own child's care before they did things for him"*

A further illuminating comment is quoted in full since it is interpreted to enhance maternal coping during a period of heightened stress:

"My son vomited blood - I almost fainted, but the nurses were there. They made me feel I could cope and so I did. I'm glad I was able to be involved in this and was allowed to do things for him, changing his clothes mopping his brow and comforting him - he needed me most then"

The sensitivity of the staff in this situation bears witness to the commitment to enhance parental confidence and confirm parental competence. It would have been so convenient to usher the mother out of the ward and offer her the statutory 'cup of tea'. Instead, the nurses are seen to implement their commitment to parental involvement in the child's care and as a result, this mother's perception of a frightening and stressful event is a positive one. The converse may have signalled to this mother her failure at a time when her child "needed me most."

Further comments from mothers indicate satisfaction that the maternal role was fulfilled, for example:

"Being able to stay with my daughter...they accepted that a child needs her Mum"

As addressed during interpretation of the children's responses, the nursing staff are also attending to the mother's need to be with her child and to maximise the perception of control. As one senior staff nurse succinctly put it during our coffee break together: (quoted with permission)

"You know the Mums who are anxious whether they show it or not, you know the ones you have to encourage to become involved..to say -come on mum, you 're the expert here"

In addition to the above insightful comments parents (37) also made what has come to be known as the 'inevitable perceptions of satisfaction with hospital care' (Fitzpatrick, 1990). In addressing this issue, I would like to propose that, in the context of the child recovering safely from surgery and returning home, a central factor of influence in the parents subsequent response to questions about satisfaction with care must be the feeling of relief felt when the experience is safely behind them. This is seen to be linked to the symbolic literalism described in an earlier section as some parents report that they will be able to 'cope with anything as long as she is safely home'. In fact this study selected the period of two weeks post transfer home as being an appropriate time-scale for the influence of such issues as the relief factor, parental exhaustion and continuing child care to be more likely to be minimal confounding variables

Discussion.

Satisfaction with In-Hospital Care

Given the difficulties which are implicit in eliciting any 'real' measure of satisfaction from recipients of health care, this study yields some important findings. The central element of the responses which in my view confirms the 'trustworthiness' of the interpretation, is that of the criteria of satisfaction being parent defined rather than provider defined. Not only did the parents indicate the degree of satisfaction they experienced, they also (with only few exceptions) went to discuss, sometimes at great length and with obvious feeling, what aspects of the care they felt moved to single out and describe. The responses were all constructive, some negatively phrased while others were very positive.

While firmly grounded in the data, I view the discourse here as reflecting on its own way of speaking, while attending to the different layers of meaning within the discourse. Contradictions between different ways of describing the same emerging issues, for example, satisfaction with the manner in which the nursing role was implemented also led to expressed satisfaction with the facilitative approach to implementing the parental role. These contradictions are confronted and following a period of the researcher standing back and reflecting on the context of the discourse, the interpretation gained is a 'new creation'

(Macleod, 1990), a synthesis of the horizons of both the text and the interpreter. This interpretation highlights some important issues, for example, the association between knowledge and knowing. Reference has already been made to the relationship between cognition and affect (p218). Some mothers pointed out that while they had all the information, they appreciated the nurses lack of assumption about parents knowing, for example:

"They did not mind my asking the same question over again, they seemed to understand how difficult it was for mothers to take everything in when they are upset about their child"

and similarly:

"I was impressed by the empathetic understanding, even as a professional I did not feel at all embarrassed to admit that I needed continued support from the staff"
(mother is a psychologist)

The effect of emotion and the impact of information given has not been specifically investigated in the context of parents concerns about their child in hospital. Professionals are well aware of the need for repeated 'small doses' of unhappy or distressing news when they are imparting information to the parent. However, a similar situation is observed in parents whose children are undergoing more 'routine' procedures. The opportunity for reappraisal in the light of repeated or new information is presented to parents at varying levels of the coping process, and in a way that can be assimilated according to the present emotional climate. As the understanding gained of satisfaction at the earliest stage of the process (the clinic consultation) has shown, there is a clear need to present continuing information to parents from the point of the initial consultation. That is; to view the assessment of the child's presenting condition as the first stage in the child and parent's adjustment to the treatment plan and to continue support as the parent works through the process of consent. Further factors which influence the perception of satisfaction relates to the practical facilities available, in particular, the presence of rooming-in facilities. However, the need for such facilities does not necessarily correlate closely with the uptake of these facilities, as the example of the mother experiencing difficulty with the care of her three month old baby indicates. This mother refused rooming-in facilities for 'personal reasons' and subsequently was able to visit her child only when she was able to find alternative care for her baby.

It is to an understanding of the factors which contributed to feeling of dissatisfaction with the child's care during the time in the ward that this analysis now turns.

ii) Perceptions of Dissatisfaction with In-Hospital Care

The unanimous message to emerge from the group of parents who expressed dissatisfaction, whether they were part of the group who commented on the positive aspects of care also, or whether they simply stated that they felt unhappy about the care, was the issue of parental absence during maximum stress times. As a recurring theme throughout child and parent analysis it is important to attend to the retrospective accounts of the parents and to seek an understanding of the key factors which may influence future clinical care.

A total of 58 parents commented directly on this theme and many articulated their disappointment in the philosophy of care and pointed to the contradictions within a paediatric hospital, which on the one hand provides a 'centre of excellence' in caring for the physical and psychosocial needs of the hospitalised family, while on the other hand, is viewed as a barrier to maternal involvement in the child's care at a time when mother perceives this involvement to be crucial. The following responses serve as an indicator of these concerns:

"...This I see as a big problem, no one really is to blame, the staff say there are good reasons for keeping parents away, we accept that but have to say how much it clouded the whole experience for us"

"It is a pity really, everything else was so well done, the staff were so very sensitive, I think changes could be made if the staff really wanted them. It is up to parents to make their views known"

"I felt shunted out of the ward, looking back seeing my son waving trying to be brave when I knew he was crying inside...How can mother feel satisfaction with care like that..."

"They dress it all up saying that the anaesthetic doctor feels it is safer to make sure that the child is taken along by the nurse, they say it would upset the child too much when the mother does leave...I wish that doctor could have seen the state of my Lindsay when I had to leave the ward".

I tried so hard during the time before surgery to be rational about this, after all every mother has to leave her child. I feel even stronger about the business now than I did before..."

"...was very upsetting for us both, the staff encourage parents to be with their child and do things for him, yet when he needs his mum most..."

The representative sample of comments reported above leads to an understanding of the depth of feeling which attends the issue of parental involvement in the care of the child, particularly during periods which, to the parent, represent the child's most vulnerable time. Implicit in the comments above is an attempt by the parent to see the staff perspective while simultaneously indicating the conviction of their own feelings. The exemption of the staff from 'blame' is seen as a further indication of the preference on the part of the parent to recognise problems within the relative anonymity of the 'system', rather than within the personnel who operate within it. Key issues arising from interpretation of the above responses include those relating to the perceived control the mother feels she has over the event, this is in turn related to the competence in carrying out her role within the hospital setting during periods of intense clinical activity. While it is the case that the parent is encouraged to be involved in her child's care, that involvement is clearly provider rather than child and parent oriented. The result is the perception of the maternal role unfulfilled. In addition, the mother may be left with a feeling of ambiguity about her level of competence in caring for her child during his time in the ward.

Within the stress and coping paradigm, this finding has important implications in relation to the coping ability of the mother, not only in the immediate situation, but also in subsequent coping demands. The relationship between perceived control and subsequent anxiety is consistently documented (Lazarus, 1984, Leventhal, 1990). In relation to mothers' coping with the surgical treatment of their child, perceptions of 'some level' of control are important in determining, not only the anxiety experienced but also the degree of competence the mother feels in fulfilling the participating role. A mother with a high level of perceived control will consequently feel more confident in caring for her child in hospital and will feel less threatened by the professional expertise of the nurses. Anxiety may then be reduced and more focused on 'real' issues, for example, the surgery per se, rather than on feelings of inadequacy engendered by loss of control and the perceived judgements of others in relation to maternal competence. The situation described is therefore that of a spiral of concerns, which can only be broken by an awareness by the staff that if the parent has the right to be involved in her child's care, then that right logically and morally must also extend to allowing the mother and child a degree of involvement also, in when to be excluded (if at all) from that participation.

A further important point relates to the very strong concern expressed by the nurses and by the anaesthetist; that is, that the child should arrive in the operating theatre in a calm, composed state. Gough, (1990), expresses this concern more directly when he points out the risks to the child's airway as well as the dangers of cardiac arrest during the operation when the child is extremely upset prior to induction. In addition, post operative bleeding

is more likely to occur, (as poignantly expressed by Dawn's mother in chapter 3) in the child who has been crying inconsolably before operation. Interpretation of the data above leads to an understanding of the mothers concerns for the manifest upset of her child when the mother is expected to leave the ward.

These important issues, tentatively reviewed above, will be readdressed in the final chapter in relation to the implications for change suggested by the findings from this study.

Other areas of dissatisfaction were expressed and are simply mentioned here, although again, the implications for nursing practice are recognised and will be disseminated. These areas include the following:

1. Facilities and resources. Concern was expressed by some parents for the limited number of rooming-in facilities. On further investigation of this point I discovered that at the time of this study, more than the average number of parent's rooms were occupied by the mothers of very sick children from other wards. Similar complaints were raised about the lack of a non-smoking sitting room for parents who expressed the need to take time out from the intensity of the child's needs for a short while. One mother commented:

"Not only was the sitting room full of cigarette smoke, but there were also some distressed parents in there, ...hardly a reassuring break"

While another went on to say:

You need to get away, the cafe is so far away at the other end of the hospital and is only open until 4 p.m. There is also a desperate need for somewhere for mums to freshen up...to keep up their morale".

There has been saturated coverage of the structural inadequacies of the Sick Children's Hospital. These needs are currently being addressed by fund raising efforts, the money raised being earmarked for the building of a new surgical wing which will, it is envisaged incorporate facilities for parents. It is outwith the scope of this study to comment on the socio-political issues which drive present health service funding.

2. Complaints in relation to communication.

A few (9.5%) parents felt very unhappy about the information received and the presence of contradictory advice given by the nursing staff.

"I was told two different stories about the anaesthetic, this caused a great deal of distress when we were already up-tight"

The importance of accurate and supportive information has already been discussed (11:3)

Attention has to be given to the context of the conflicting information, the perceived needs of the mother at the time and the specific content of such information as well as the knowledge of the informer. While it is the case that on a few occasions, the technique for induction of anaesthesia varies, that is mask *v* intravenous induction (necessitating an injection) the children are well prepared for the specific nature of the induction, since they are all taken to the operating theatre the evening before surgery and explanations are offered. It may be the case that on the above occasions, the staff responsible for communicating the information to the parent were unclear and stated either approach, or mistakenly stated the wrong one. Parents under stress require concrete 'givens' and are, on the whole unable to assimilate an either or debate when it relates to the maximum sensitivity and stress of the anaesthetic procedures.

iii) Preparation for Transfer Home.

One father respondent made the comment that while communication was 'good' he would have appreciated being told more about the operation *per se*.

"He had a very swollen painful tonsil when we got home, I was not prepared for this"

Clearly this father had not been prepared for the post-operative discomfort routinely expected. In fact, all parents are given a printed information sheet which details the care required on transfer home. A balance has to be drawn between causing unnecessary anxiety to the parent and running the risk of the early signs of complications being undetected. This is a further issue which has implications for the nurses role in attending to the subsequent care of the family.

Further comments from parents indicated that they still felt unsure whether surgery had been justified (6 occurrences-control groups). This was mainly in relation to the lack of improvement in the child's hearing two weeks post transfer home. This raises a further important clinical issue. That is; improvement may be immediate in some children, while in others, a time lag is necessary between surgery, the time for post-operative swelling to subside and subsequent improvement in the child's hearing. Reference to the interpretation of the child's recovery and to the parents' perceptions of how the child coped overall with the experience (10:9), confirms the need for a longer period of recovery than most parents are prepared to expect. These issues have implication for the way in which parents are counselled by the nursing staff prior to the child's transfer home.

Other problems raised in this section include parents being unprepared for the taxing demands of the child during his recovery period at home. Many mothers mentioned the fact that they were already exhausted by the events leading up to and including hospitalisation. Homecoming was looked forward to with much anticipation of some

respite for the mother. In fact 23 mothers pointed out that they felt unable to cope with the continuing emotional and physical demands of a child who still felt miserable and needed a great deal of nursing. During the period of data collection nurses were heard to advise mothers to rest as much as possible and to be aware of the demands of the child when he was transferred home. Family centred care, although practised within the context of emotional support and practical help given to parents of children in hospital, has obvious limitations. The existence of support at home, in the form of family or caring neighbours is thought to be the only way to circumvent this very real drain on the physical and emotional resources of the parents after the child's homecoming. The implications for practice appears to centre on affording this important issue a higher profile during the event. The problems attending this approach are of course, those of the concern being misinterpreted by mothers who are already in a state of heightened arousal and thereby increasing anxiety. Alternatively, the concern may be ignored by the parent who sees the care of the child as a priority and 'can cope with anything as long as she is safely home' (10:6).

11:6 Summary of the Main Findings.

The discipline of selectivity has been a key concern to me throughout this analysis. The sheer volume of illuminating data harvested from parental responses, required that I attended to those key areas of parental responses which would not only address the research questions but also contribute to an understanding of the child responses. The insights gained are conceptually linked throughout.

The emphasis of the nurses' role is on delivering a prescribed approach to care after the child is admitted to hospital. This approach addresses the specific nature of the specialist procedures performed. The routine within which the staff operate serves an important purpose, that is to ensure that the criteria of physical care demanded by the specialism are met and carried out to an acceptable standard. Paradoxically, despite appearing to operate within a specific *modus operandi*, the nurse is able to offer a remarkably individual approach to care. This is an example where the needs of the family rise above those of the institution. The implications of the findings for nursing practice will be addressed in the final chapter.

The researcher as interpreter comes into the act of interpretation with a set of personal pre-conceptions and a theoretical lens (Kuhn 1970). Through the process of interpretation these have become more clearly articulated in relation to the text. Gadamer, (1975) makes the point that interpretation is a process imbued with time. The horizon of the present is being continually formed in that we have continually to test our prejudices. Throughout

this interpretation of parent's responses the horizon of understanding is tested and reformed through the process of dialogue with the text. The goal is not to understand the text but to understand something in front of it, the human project (Heidegger, 1962, Rabinow and Sullivan 1979).

The main findings relate to the parental commitment to accept the medical treatment for the child and the degree of voluntariness which the issue of proxy consent finally yielded. The control groups report greater difficulty coming to terms with the 'decision' to accept surgery on behalf of the child. It has been argued that this is because the decision was not actively made by many parents within the control groups but was rather a passive decision as the parent was observed to 'swim with the tide of consultant opinion and later, staff expectation.' "...Very unsure about all this, but now we are here they all expect us to go through with it, ...there is no mention of are you sure you are doing the right thing..." Interpretation of the effect on subsequent coping of the parents led to an understanding of a qualitative difference between the groups. That is; less channelled and less managed coping efforts were interpreted from analysis of the control groups' responses. While the experimental group were seen to focus on the reality of the event and its outcome, the control groups were in many instances, still struggling with the issue of proxy consent at the eleventh hour. The point has been made that proxy consent is a process, the first stage in that process being the initial clinic consultation. The control groups received no further support in their decision until the day of admission when some parents indicated that 'it was too late then, the decisions had been made'. The benefit of the experimental preparation in terms of the parent coming to terms with and being helped to re-appraise the decisions made on behalf of the child, has been shown to be an important aspect of the intervention.

Further case analysis looked for a link between child manifest upset and uncertainty; between age of the child and uncertainty; and between social class and uncertainty.

While some children within the control groups were distressed prior to and during admission, so to were some children within the experimental group. No clear group difference was apparent. The issue of the influence of age of the child was addressed throughout this analysis. Previous empirical studies cite age of the child as a key predictor of mother's distress (Mishel, 1987). The present findings support the studies which identify age of the child as an important factor in the manifest upset of the *child*, however, age of the child is a secondary consideration in the maternal anxiety reported in this study. Other key factors discussed above, for example, issues of control and fulfillment of the maternal role, as well as commitment to the prescribed surgical

procedures are identified as central variables of influence in maternal anxiety.

The issue of social class is less clear. Reference has been made throughout this analysis to the effect of social class on the expectations of the parents, particularly during the clinic consultation. While it is the case that parents within the lower social groups appear less assertive and more trusting of the professional's role, this group are also less anxious overall. No link was found between social class and commitment to the child's treatment plan. This clearly suggests that some parents within the lower social groups also had difficulty in coming to terms with the decision to accept the necessity of surgery. This is an expected finding in the light of the 'trusting acceptance' of this group, some of whom commented that 'it was not up to them to question the doctors decision'.

A reciprocal model of child/parent anxiety, which in previous studies has been found to operate at varying levels during the hospital treatments of the child was not upheld by the findings from this study. Indeed, a striking absence of emotion contagion was noted in the responses of some children whose mothers were extremely anxious before and at the point of the child's admission. Factors within the child, for example resilience, as well as factors within the ward milieu, for example, primary nursing and the general aura of 'normality' may have combined to protect the child from the effect of overt and covert maternal anxiety. Reference has been made earlier in this section to the possible factors which transcend the immediate situational stress of the parent coping with the imminent surgical treatment of the child. It is apparent that an exploration of the personal dynamics which attend maternal expressions of anxiety may cast further light on the genesis of this anxiety. The hidden agenda, while clearly directed at the child in hospital, may also be the vehicle for the expression of other important anxiety evoking factors in the parents life. These factors have not been teased out by this analysis. It is also evident that the role of the researcher was, in many instances perceived by the parent to be a listening and sharing one. A role in which a facilitative atmosphere encouraged the expression of parental feelings hitherto unshared, even by the respondents closest family on some occasions. The potential for this important role to be made explicit and to be offered as a facility for parents much earlier in the coping process is an unexpected finding.

The influence of the parent's perception of, to what extent their role was fulfilled during the in-hospital treatment of their child was found to be an important predictor of parental coping. Cross reference with the expectations in relation to their role (which were recorded pre-admission), provides some valuable insights which are now explored.

The group of parents who were seen to be 'laying the ground rules', it is recalled, stated exactly what they expected in relation to staff/parent co-operation during the period of the child's treatments. The main area of concern raised by this group during the written post-hospital responses is that of maternal absence during the maximum stress times. In addition, some parents within this group also made reference to the unsatisfactory nature of preparation, compared with other families in the ward at the time (this is a reference to communication with families prepared within the experimental treatment group). The confounding effect of all groups being in the ward at the same time clearly raises questions about the validity of the retrospective responses in relation to preparation. It has to be asked, would the control groups have raised the question of the potential benefit of a pre-admission preparation programme if the experimental group had not communicated the inherent value of this to the control group parents. It is not possible to give a definitive answer to this question. It is however important to recall the level of dissatisfaction expressed by parents during the admission interview (that is before 'contamination' by the views of the treatment group), in relation to the preparation received by way of the information leaflet and also in relation to the unsatisfactory nature of the clinic consultation.

The group of parents who appeared diffident and uncertain about their expectations did on the whole report feeling very satisfied with the outcome. Satisfaction in this group was perceived as being particularly child and parent defined. For example, the mother detailed the aspects of care which her child felt particularly happy with, as well as the aspects of care she herself singled out as being commendable. Important areas identified include those mentioned during the analysis, that is the parent felt in control of her own child and was encouraged by her level of involvement at all levels of care. Comments made in relation to the child's feelings of satisfaction, although not specifically requested on the questionnaires included:

S/he was happy with the way the nurses talked to him/her...took time to read stories when Mum was away...knew all about him/her...talked about his/her family...

It is appreciated that the above comments indicate parental as much as child satisfaction with care. Again, integrated with indices of satisfaction, are comments made by this group about the disappointment they felt when asked to leave the ward and not return until the theatre list was over. It is interesting however to note that these complaints were phrased in a more apologetic way, an attempt to find mitigating circumstances and to

remove all 'blame' from the nursing staff.

The final group of parents, that is the 'defensively hostile' group did on the whole, make very positive comments about the level of care they and their child received, countered only by the wish that they had been prepared for the wrench of having to leave their child at the perceived maximum stress.

At the outset of the analysis, I adopted the position that each approach to analysis should be equally valued. That is; the quantitative analysis, although presenting a different perspective, would make an equal contribution to answering the research questions. This was a naive expectation. The richness of child and parent experiences which has been shared with me has quickly led to the realisation of the complexities and inter-relatedness of meaning in context - a meaning which could only be teased out by an interpretive analysis of the qualitative data. Meaning is, and must be a product of human consciousness. It is the way in which the researcher connects the parts to each other to provide a meaningful concept of the whole. The quantitative analysis indicated a high level of maternal anxiety across all groups. From this perspective it appeared that the experimental group had more difficulty managing this anxiety than the control groups. Interpretation of the qualitative analysis led to the understanding of the real dimension of anxiety across the three groups and highlighted important qualitative differences in coping with it. Reference was made to the quantitative analysis as a conceptual bridge between the data sets, this has served an important function, that is to provide a clear frame of reference for exploration of the meaning of the events to the parents as they prepare for, and experience the stress inherent in the surgical treatments of their child.

Attention now turns to a discussion of the findings, prior to addressing the implications of this study for the development of nursing knowledge. The final sections will then consider the generalisability of this work to other paediatric settings and the potential for further research in this area, prior to addressing the limitations of the research.

CHAPTER 12

DISCUSSION OF THE FINDINGS, THE DEVELOPMENT OF NURSING KNOWLEDGE, IMPLICATIONS AND RECOMMENDATIONS.

12:1 Introduction.

This chapter is concerned with a discussion of the findings. Attention will then turn to the implications of this research for the development of nursing knowledge. The inter-relationship between research, nursing practice and the development of nursing knowledge will be explored in this discussion. An indication of how the findings may be shared with professionals engaged in clinical practice as well as other researchers will be given. This is considered to be particularly important, not only in relation to the impact of the findings on the potential well-being of the children receiving ENT treatments, but also in relation to the development of nursing knowledge and the importance of stimulating further research initiatives by the critical appraisal of this research by colleagues.

Tentative recommendations based on the findings from this research will be made within the context of current health service funding on the one hand and the the need to progress towards an excellence in care on the other.

The limitations of this research will be reviewed, this will include a comment on the methodological issues arising. The generalisability of the study findings to other paediatric settings will be considered in the light of the key issues arising from this study. Finally, the potential for the development of this and of further studies which examine the emotional well being of children and their parents during paediatric hospitalisation will be examined.

12:2 Discussion of the Findings.

In drawing together the salient findings from this investigation, the key issues arising from analysis of the quantitative and both sections of the qualitative data will be summarised.

This study set out to examine the responses of children and their parents to the child's admission to hospital for elective surgery, within an experimental approach to preparation.

The sample in this study (n=90) were children within the age range 3-7 years, all of whom were on the ENT waiting list of a Regional Sick Children's Hospital. The children had no previous hospital admissions. The only contact the children had with health care was the recurring ENT symptoms, which necessitated intermittent visits to the family doctor. Random sampling secured an adequate across group 'match' on social class, family size, sex and marital status of the parents (chapter 8).

In accepting the premise that hospitalisation is a stressful experience for the child and an anxiety evoking experience for the parent (Azarnoff, 1984, Peterson, 1989), the research was designed to investigate the efficacy of an experimental intervention in mitigating the distress to child and parent.

The research questions reflected the temporal sequence of the stress and coping process which formed the framework of this study. That is; beginning with the pre-admission phase, through in-hospital adjustment to post-hospital outcomes. The dynamic nature of stress and coping within the medical setting was thereby incorporated in the design.

The Research Questions

In addressing the research questions in this integrative discussion, the evidence garnered from the analyses will be presented in relation to the clearly identified phases of child and parent experience. These phases were ;

- i) The Pre-admission phase
- ii) The In-Hospital phase and finally,
- iii) The period of adjustment following transfer home, which included parent's perceptions of satisfaction with the process of their child's hospitalisation and surgery.

The temporal sequence identified throughout the three sections of the analyses, is consistent with the stress and coping process. This approach affords congruity and underlines both the progressive nature of the experience and the necessary and close inter-relationship between the various aspects of child and parent responses.

An understanding of responses throughout the first phase of the experience, that is the pre-admission period, was informed by the following research questions;

- 1) Will the experimental intervention, based on identifying and meeting the needs of the individual child and his parents in relation to preparation for hospitalisation, influence the level of stress experienced by the child, before admission and during his stay in hospital?

2) Will parental perceptions of anxiety, and coping before admission , be influenced by the nature of preparation received by child and parent?

In keeping with the integrative approach adopted in this discussion, the experiences of the parents during the pre-admission phase will be addressed in concert with those of the child.

The qualitative data highlighted the importance of the pre-admission phase of the experience, particularly in relation to the genesis and intensity of child and parent anxiety (11:3). This is an important finding. The quantitative data contributed to an understanding of the frequency of child and parent anxiety. In this integrative discussion the value of considering both quantitative and qualitative data at different stages of the experiences will be reviewed.

The following discussion will therefore explore the pre-admission phase of the experience in some detail, since parental perceptions of the pre-admission experiences have been found in this analyses, to influence later outcomes.

The Pre-Admission Phase.

Two clear stages were identified within the pre-admission phase. The first, the referral stage, involved the initial clinic consultation. Prior to this phase, contact with the family doctor, who then assumed responsibility for initiating hospital referral was made by all families. The purpose of the clinic visit was to evaluate the needs of the child and assess and discuss the treatment options most appropriate to the needs of each family.

The second phase of the pre-admission process began as the parent and child assimilated and came to terms in their own way with the treatment plan proposed. The parent had the additional coping task of working through the process of informed proxy consent, as well as preparing the child for the forthcoming events.

The impact of the initial clinic consultation will now be discussed in relation to the subsequent coping of the parent and adjustment of the child as they prepared to enter hospital for planned paediatric surgical treatments.

The Clinic Consultation

The findings identified the central importance of the initial clinic consultation in influencing subsequent parental coping with the experience. Interpretation of the responses of parents to the consultation alerted the researcher to the need to examine the factors within the clinic milieu which may be perceived as facilitative or non-facilitative in

relation to the coping efforts adopted by the parents.

The inherent potential to view the initial contact as a positive contribution to subsequent coping is an important finding which has hitherto been unaddressed in relation to paediatric elective surgery. It is therefore considered appropriate to present a backdrop against which an understanding of the power and authority of the clinic *per se* may be understood in relation to the conviction of the parent's responses about this important phase of the experience.

The cornerstone of preparation for paediatric hospitalisation is that of offering a supportive and caring relationship to the children and their families about to enter hospital. The experimental intervention in this study presented the treatment group with support and accurate information within a climate conducive to sharing concerns and anxieties and working through the process of adjustment. This took place up to five days before admission, therefore the impact of the clinic consultation which took place between six and nine months before the experimental preparation, applied to all parents in the sample. The positive value of the intervention has been discussed (chapter 11), however, since the data are interpreted against the stress and coping paradigm, it is important to address findings which are perceived by the respondents to either limit their coping ability in the situation or to accentuate their anxiety. The manner in which the clinic functions may enhance an understanding of these issues.

This is discussed in relation to the clinic agenda and the ethos of the paediatric ENT clinic.

The Agenda and Ethos of the Paediatric ENT clinic.

Two senior consultants saw patients on two different days each week. In addition, each consultant had a registrar who saw patients independently, referring to the consultant when in doubt. No nurse was routinely present at the clinics, although on occasions the sister from the ward did organise some clinics. The availability of the senior nurse depended on the needs of the ward. A nursing auxiliary acted as receptionist and clerkess, showing patients into the room and directing them to the appropriate department for hearing tests when required. A few mothers (10) did comment on the manner in which the auxiliary conducted the clinics, referring to the aura of haste and general feeling of being hassled out of the room at the end of the consultation (p 270).

Individual analysis of the parents responses presented in chapter 11, looked for a link between consultant seen and parental perception of the consultation (identification of which consultant conducted the clinics was made by reference to the case notes-this

information was also displayed in a prominent position above each child's bed). No such association was found. This suggested that parent factors at the time of clinic attendance were more dominant factors of influence in the parents ability to seek clarification. For example, interpretation of the setting as facilitative or restrictive was influenced by factors such as social class, previous experience of health care and the concerns of the parent at the time of the consultation which, it is realised, may transcend those concerns directly related to the child. It is the nature of hermeneutic enquiry to attend to understandings gained at one level of interpretation and ask how they influence those understandings gained at a later phase. This was evident in the impact of the initial consultation on the coping responses and satisfaction with care reported by the parents. Therefore the clinic agenda was a recurring issue throughout the analysis of child and parent responses and was identified as an area which required to be specifically addressed.

The data suggested that the supremacy of medical authority over-rides consideration of the parent's need to be actively involved in the decisions made. Interpretation also, however indicated that the parents were initially happy to go along with the strong decisive stand adopted by the doctor (11:3). The data indicates that some parents actually *expected* to relinquish control at this first consultation and were seen to selectively attend only to those aspects of the experience which they were unable to ignore.

"They are the experts, they know best" "What is the point of seeking advice if you are not prepared to take it" (p11:3)

The notion of primary and secondary control described by Rothbaum, Weiss and Syder (1982) is a salient issue. This notion would suggest that the mothers who perceived they had no actual control (primary control) over the decision to elect surgical treatment on behalf of the child, may have employed secondary control measures (avoidant coping) which filtered out the perceptions of lack of control. This avoidant coping, as has been mentioned, proved to have short term effects, since the issue of control and commitment to the procedures re-emerged as an important concern to the control groups, at the point of the child's admission. This concern was interpreted to influence the parent's adjustment to the admission process in that the anxiety reported by the parents who remained uneasy about their commitment to the procedures was reportedly higher and less controlled than that experienced by the parents in the experimental preparation group who perceived themselves to be 'well-informed and accepting of the events'(p275-77). The efficacy of the

treatment condition was therefore apparent in relation to the opportunity presented to the experimental group for further information and subsequent re-appraisal of the meaning of the forthcoming events; and the parents commitment to the treatment plan.

As discussed in chapter 11, proxy consent is best viewed as a process. In this context, the initial consultation may fulfil the purpose of identifying the problem (recurring ENT symptoms) and suggesting ways of circumventing it (surgery or 'wait and see' policy).

Some parents entered the pre-admission period lacking in commitment to the surgical procedures proposed for their child (p 270). This was reflected in the acute anxiety expressed by many mothers in relation to the wisdom of the decision made to proceed with the ENT surgical treatments for their child. All mothers who expressed that concern were in the control groups. The important element of control as an effective coping aid was therefore absent, since the group of mothers who perceived their involvement in the proxy decision to be passive, reported the anxiety to be directly related to their overall feelings of helplessness and on occasions, inadequacy in the situation. *"...If only I had known a bit more about it all I wouldn't have felt so useless" "I am so anxious about it all...I am really tempted just to take her home and forget about the whole thing..."* (p 278).

Maternal perceptions of competence in caring for the child during his time in the ward were considered to be influenced by the lack of control experienced at the outset of the coping effort. The effect of the perceived lack of control was found to be associated with an increased level of anxiety . That anxiety was non-focused and at times appeared out of control. Similarly, the influence of parental anxiety in relation to the confidence with which the parent envisaged her role in caring for her hospitalised child was found by this analysis to be important (p301).

This important finding, which may potentially present a fresh approach to conceptualising stress and coping within the paediatric health care setting will be discussed in relation to the development of nursing knowledge in a later section of this chapter.

Why are parent's perceptions of the clinic consultation negative and the imbalance of information within the clinic so great? The data signal an important issue which casts some light on these questions. That is; the professional perception of the nature of the proposed surgical treatment. Reference was made by some parents to the "impression that it was all routine" that "things should be kept low key" (11:3). While never explicitly stated within paediatric clinics, the parent's responses suggested that ENT treatments were viewed by the professionals as 'minor' elective procedures, for example, "It is all so

routine to them...I know 'they' see it as a small operation...but when it's your own son..."

It is important to point out that this was the perception of the parents (n= 12) following the clinic appointment, reported to the researcher some months later and specifically did not represent direct responses from the staff. However, the central concern is that the parent went on to *believe* that this was the attitude of the medical staff to the procedures. (It is reiterated that no nurse was routinely present at the clinics). The danger inherent in this approach, which may be intended to convey reassurance to the parent, is that the assumption was made at the outset, that all parents would *be* reassured by playing down what is to many families, a first contact by a close family member with hospital and particularly with surgical procedures involving anaesthetic.

Lazarus (1982) refers to the 'trivialisation of distress' (p.111), as a mechanism which suppresses effective coping efforts and directs the individual towards a pattern of avoidant coping. The data clearly show that this was the case, in that the parents who were unable or unwilling to articulate their fears, described an avoidant pattern of coping responses (p280). Parents need to know that 'it's alright to feel anxious'. Suppression of natural feelings of concern lead to uncontrolled anxiety (Trad, 1987). The data in this study highlighted the lack of support experienced by many mothers when they attempted to express and seek reassurance of, their natural anxieties. In many ways, mothers were left feeling that they had failed to cope with the stress in the pre-admission period. *"I tried to talk to my husband about it but he told me to get a grip of myself and stop getting things out of proportion"*.

In the situation, the mother was the victim - not only of the anxiety engendered by the forthcoming admission of her child, but also by her perception of other peoples judgements. These included the perceived judgements of the professionals whose stated goal it was to allay apprehension as well as that of the immediate family who potentially, were able to provide most important support at this time.

The absence, not only of appropriate information given to each family, according to their individual needs, but, as suggested by this analysis, the absence also, of appropriate support was identified as a concern felt by the parent (p284-6).

The expectation to accept medical advice unquestioningly, was a powerful force in shaping parent perceptions. Parents (n=25) reported their belief that they should *"accept unquestioningly, medical advice, since it is given in the child's best interests"*.

The family, particularly if exposed to the hospital milieu for the first time, spend much emotional energy attending to the general aura created by the clinic (personal experience of the writer). It is not surprising that some parents enter the consultation little prepared

for the entirely factual, brief contact time with the expert and even less surprising that parents report their inability to reflect appropriately on the content of that consultation and ask 'sensible' questions.

The data have shown that children go onto the waiting lists and their parents receive no further information or support until the point of the child's admission. The preparation and support offered to the child is that which the mother can give within the context of her own knowledge and anxieties. Interpretation of the data in this study has shown that it is not necessarily the amount of information imparted, but rather the manner of its sharing. The concept of sharing, of achieving a balance between prescriptive and facilitative communication, as well as the potential to view the clinic consultation as an important coping resource for child and parent, are therefore a central issues which require to be addressed in relation to fulfilment of the nursing role. This will be considered in a later section of this chapter.

Summary of the Pre-Admission consultation.

The manner in which the clinic as a 'therapeutic sorting office' (Strachan, 1992), functions was sharply criticised (chapter 11). Many researchers have made reference to the purpose of the initial consultation as the first stage in the decision making process (for example, Alderson, 1990). It was the first and the only stage in the 'process' as the parents in the sample were not followed up and given support as they attempted to work through the factors which would ultimately shape their decision and the manner in which they subsequently coped with the events.

Having discussed the referral stage which was informed mainly by analysis of the qualitative data, attention now turns to a discussion of the immediate pre-admission phase.

The Immediate Pre-admission Phase.

This period was necessarily limited to an examination of the responses made by child and parent which were seen to reflect their coping throughout the few days leading up to the child's admission. Quantitative and qualitative data provided differing perspectives from which understanding of child and parent experiences were interpreted. As has been reviewed in the 'Method's' section of this thesis, the purpose of the approach of triangulation applied to this study was to achieve a balance between the objective and subjective in an attempt to tap the reality of the experience as reported by child and

parent and which was seen to reflect the specific nature of the experience at the time of its sharing. The differing perspectives offered by the two approaches to data collection were exemplified in the analysis of parental reports of anxiety immediately preceding the child's admission.

The key point which required to be addressed in relation to this finding was the intent and purpose of a quantitative and qualitative analysis *per se* (chapter 7). The quantitative analysis provided important data on the frequency of parental anxiety and cross-tabulations were made to assess the influence of key variables on that anxiety, for example, age of the child, and preparation (appendix-table 9). From that frame of reference, the interpretive analysis went on to explore the parent's account of that anxiety. In this way, the qualitative analysis came as close as reasonably possible, to exploring the personal meaning of the experience. Assessment of the impact of the 'hidden agenda', that is the influence of the past history of the parents was outwith the scope of the investigation, although previous experience of stress in the children was considered to be an essential measure when investigating the responses of the child to the stress of the health care setting (Rutter and Garmezzy, 1983). While accepting the potential influence of factors in the parents immediate concerns which extend beyond the surgical treatment of the child, assessment of parent's responses by way of the GHQ was considered to control 'within reasonable boundaries' the possible confounding influence of extraneous parental anxiety

Interpretation of the data presented in chapter 11 (11:3 ii), showed that maternal anxiety, while uniformly high across all three groups, led to the understanding of the genesis of that anxiety. The close inter-relationship between the experience at the clinic and anxiety subsequently reported by the parent during the admission interview was identified by the analysis. The emerging issues, in particular, the potential of the clinic as an important coping bridge which may help the parent and child span the waiting period, highlight important social and clinical issues.

These issues were seen to include those of parental control, perceived parental competence and the influence of these factors on the parents level of anxiety and subsequent focused coping efforts. The experimental group, while indicating a high incidence of anxiety were seen to manage that anxiety effectively by focusing on the reality of the events for which they had been prepared and to which they seemed committed. That is; the focus of concern was on the child's surgery, in particular, anaesthetic induction and his immediate post-operative recovery.

Conversely, the control groups, while experiencing a similar incidence of anxiety, went on to express important qualitative differences, which suggested a greater intensity and

diverse focus for that anxiety. The data therefore, indicated that the coping responses of the experimental and control groups were different. A problem focused approach was adopted by the treatment group while the control groups remained concerned about the soundness of the rationale for surgery *per se* and were therefore uncommitted to the procedure at the point of the child's admission. Careful examination of possible confounding variables was made in an attempt to identify factors within the control groups, other than lack of support and pre-admission preparation. For example, the incidence of single parent families, birth of a sibling, response of the child to the events, social class, age and sex of the child, family size and anxiety in the mothers. No such imbalance of confounding variables was found to apply to these groups.

The findings therefore suggested that the experimental intervention provided important supportive information to the child and parent, and presented the parents with the opportunity to work through the process of informed proxy consent, and to address directly their reservations and to consequently arrive at the position of voluntariness. The importance of child and parent travelling together towards the experience with an understanding of the preparation received by both parties, is raised by this analysis to have contributed to the overall sense of comparative well-being experienced by the treatment group. *"It was so much better to be able to prepare her on the ward as we saw it, we could talk about what really happens there, the staff, the playroom and the other children..."* (p 297)

The control groups had no such opportunity. They arrived in the ward on the day of admission, 'prepared' in the manner applied to all hospital admissions, that is, by way of the information leaflet sent out to all families at the same time as notification of admission.

The concerns of the children before admission raised important areas to be addressed in relation to parent's perceptions of their child's distress and the possible influence of parental anxiety on these perceptions. In addition, the questions asked by the children were interpreted to lend valuable insights into aspects of the experience which were perceived by children within the age range studied, to represent a particular threat or present a source of bewilderment.

The Concerns of the Children before Admission

The apparent discrepancy between the manifest upset in the child reported by the parent prior to admission (quantitative data, appendix-table 3) and that indicated by the nature of the questions asked raised important points in relation to parental perceptions of the child's coping with the knowledge of his forthcoming admission. A further more subtle point was raised by interpretation of the data. That is; an awareness of parental needs in the pre-admission period in relation to securing a calm and untroubled emotional climate. It was postulated that the parent was unable in the situation, either to recognise the significance of such anxiety laden questions asked by the child or, to respond in a manner which would meet both the child and parent coping demands at a time of heightened vulnerability. (Examples of this point are to be found in chapter 10 p.217). The rationale for this hypothesis, developed by the researcher, lies in coping theory. That is; the parent may have perceived the impact of her own concerns and anxieties to present a major coping challenge. To attend also to covert anxiety in the child, increased the demand for resources which at the time, the parent was unable to tap. It was also postulated that, because the mother was coping with the practical organisation of arranging care of siblings, work commitments within and on occasions outwith the home, as well as the general logistical planning of visiting or arranging to stay with the hospitalised child, a coping strategy which filtered out unmanageable demands, such as addressing the real level of distress of the child served a necessary protective function for the mother at that time.

The questions asked by the children, were indicative of a wide range of concerns which were interpreted to reflect the impact of the situational stress on the child's current developmental stage. The coping strategies adopted by the child *at the time of asking the questions* were also suggested by the data. The dynamic nature of the coping process was seen in the progression of questions asked by the child. For example, many children began by asking the parent about the necessity of hospital and by the end of the questions, the data suggested that the child was more accepting of the events and turned his focus to the reassurance that maternal presence would be consistent throughout the hospital stay. Interpretation of the questions asked by the child also provided a rich account of his conceptions of illness and medical treatment. The following discussion was informed by interpretation of the qualitative data, while the quantitative data yielded information about the frequency of manifest upset observed in the child prior to admission (appendix-table 3).

The findings upheld previous empirical studies which indicate the importance of considering children's health knowledge and beliefs within the context of his cognitive development. For example, the child's conception of hospital admission as a form of imminent justice has been explored (p212). Statements about health beliefs constitute an important source of information to professionals who care for children because they reflect the child's general level of emotional and cognitive functioning. An age related finding was apparent. Pre-school children tended to view medical treatment as a form of imminent justice, in particular, younger children in this sample were seen to engage in bargaining, for example, the promise of 'good' behaviour, or apologies for past misdemeanours, were presented to the parent in an attempt to exempt the child from admission. An important development of this finding may be the need to prepare well children for possible future health care treatments. This issue, discussed in chapter 4 has not hitherto been addressed in Britain to any real extent but appears particularly salient in view of the positive effect of the preparation programme on the younger children (10:12). These children were able to accept the forthcoming admission in a more benign light and were perceived by the parent to feel less threatened by the event.

Personal meaning of the events is a central construct in stress and coping theory, also articulated as 'significance theory' (Bailey and Clarke, 1989). It has been hypothesised in chapter 10 that the nature of the questions asked did portray aspects of that personal meaning. Given the importance of the child's past history in shaping current perceptions, the quantitative findings elicited information about the previous stress experience of the child (Table 4 and appendix-table 1). A constant concern expressed by children across both age ranges was that of separation anxiety. This reflected not only the natural need of the child to have mother present at times of stress and increased vulnerability, but also the mothers need to be there, to assert her right to become involved in the care of her child from the outset. The analysis also suggested that in the absence of control in the initial decision making, the parent may have attempted to redress the balance of that control by indicating, by way of the emphasis placed on the child's questions, her right and expectation to 'be there.' The mother as a mediating influence in the child's appraisal of the stressor is implicit in coping theory. That is; the potential of the parent to act as an effective coping resource for the child by providing a familiar supportive presence in an unfamiliar and variously threatening environment. 'Contingent coping' ("*I will go if you stay with me*" "*...as long as you are there too Mum*") was therefore a recurring observation made in the analysis of the children's questions. (p.217).

The quantitative data showed the incidence of child anxiety in the days preceding admission to be lower in the treatments group (appendix-table 3). The effect of the experimental treatment in mitigating pre-admission distress appeared to be beneficial. The majority of the treatment group indicated to the parent, positive responses between the preparation event and subsequent admission. Age was identified as a significant factor in this study in predicting the emotional response of the child in anticipation of the stressful event. This finding is consistent with other studies which also show the pre-schoolchild to be more overtly distressed prior to the event (Thompson, 1986, Peterson and Brownlee Duffeck, 1984). An important finding in this study however, is the effect of the preparation on the younger children in the sample. The beneficial effect of preparation was perceived by the parent to be consistent across all age groups, therefore the pre-school children in this sample were seen to display positive outcomes in relation to adjustment to hospitalisation in the few days leading up to admission.

Support - A Viable Construct in relation to Elective Paediatric Treatments?

The data consistently identified absence of appropriate support during the pre-admission phase as being instrumental in the high level of anxiety experienced by the parents.

What constitutes support in the context of a parent preparing her child for admission to hospital must be addressed in relation to the reality of individual family circumstances, for example, the presence of factors which enhance or restrict the ability of the parents to find that support in the context of home and family.

The few parents who found support in the context of home made reference to the sense of relief they felt when someone cared to enough to listen. The source of that support was not a skilled counsellor, but often a neighbour who could share the anxiety and in that sharing helped the mother to find her own coping strength.

An over-riding concern in discussing the findings of this study was the absence of support given to all families after the clinic consultation. Parents reported that they returned home at times uncertain and frequently anxious and confused, about the proposed treatment plan and more specifically, about their influence in the decisions made (11:3). While many parents reported a sense of relief at having the problem dealt with, they went on to find their subsequent adjustment hindered by the lack of supportive information. This was particularly apparent in relation to the fundamental underlying issue of their commitment to the consent process.

In addressing the construct of support prior to elective procedures, the data have raised an important issue. Attention requires to focus on how that support, which was clearly stated by the parents in this study to be necessary, can realistically be given, within the context of a busy and generally brief, ENT consultation. This will be addressed during discussion of the recommendations arising from this research.

The responses of the children during in-hospital care are now discussed. This phase of the experience was informed by 'blind' observer ratings of manifest upset and co-operation and further informed by the parent's perceptions of how the child coped overall with the experience. Phase two is therefore informed by quantitative and qualitative data.

Phase 2

Children's Coping during In-Hospital Treatments

During the treatments, children prepared for the experience within the experimental condition, appeared to cope well and co-operate fully with nursing and medical procedures. The distress noted within the treatment sample, was either of short duration, in relation to a specific event, for example, transfer to the operating theatre, or was linked to maternal absence; an event which most children found distressing to various degrees. An important finding is the absence of non-category responses made by the nurse observers on behalf of the children in the experimental group, thus indicating no extreme distress. The non-category response it is recalled, relates to the comments made by the nurse observers of children's behaviour which was outwith the five categories presented on the upset and co-operation scales (instrument no.5). It is pertinent however, to point out the difficulties experienced by all children with post-operative eating and drinking (10:9). Part of the preparation for post-operative care, involves the nursing staff informing each family on the day of admission, of the importance of drinking and eating in the early post-operative period. On the whole, the older child had more difficulty swallowing the day after surgery. It could be inferred from the analysis, that younger children did not necessarily associate swallowing with pain, therefore had a lower expectation of pain when asked to eat and drink. Strong emphasis is placed on the importance of resuming normal eating habits in the days following ENT surgery. Indeed this was identified as a further source of maternal concern in the pre-operative period (p238 and p248). It was suggested by the interpretation of mother's responses that the pressure on the mother to ensure that her child eats and drinks normally after surgery is in fact counter-productive. A more relaxed approach, one which takes into account the child's perception of the pain experienced as well as the risks involved in identifying as a problem *a priori*, that which

should be accepted as normal healthy practice, may be a more fruitful one. This will be considered when the recommendations are addressed at the end of this chapter.

The responses of the children during periods of maternal absence (when the parent envisaged her continued presence to be particularly central to the child's well-being) are seen by the analysis to signal fundamental concerns. These concerns related to the level of parental involvement in the child's care. The responses of the parents led to an understanding of the very strong conviction held by many mothers of their right to continue to care for their child at *all* stages of the experience. The findings suggested a dichotomy between what the nurse perceives as being in the child's best interests and the parent's perception of the same goal. Far reaching implications for nursing practice, not least of which is the level of commitment to family care envisaged by the nurse, were raised by the findings. Part of the benefit of attentive listening is to accord real worth and significance to the other persons own perceptions. Nurses, while aware of how the mother felt were perceived by the parent to be unable to influence the rigidly adhered to ward policy, which, in this instance was medically defined. The effect of this conflict was that mothers were asked to leave the ward during the period when they *were acutely anxious about their child's well-being and were concerned also about the outcome of surgery.* The parents also indicated that they felt they were abandoning the child to the care of others at a most sensitive time. The outcome of this negative experience is that of mother's feeling less competent in the care of their own child during the more 'technical' aspects of care. The impression held by some mothers was that of *"this is no time and place for the mother, the nurses are the experts here"* (reported on PHBQ). This perception clearly contradicted the underlying philosophy of nursing care adopted in the ward. It was suggested by the analysis of parent's responses that the parents perceived the nursing staff to be empathetic to their concerns, but unable to respond in a manner that would resolve the conflict. For example, responses on the PHQ;

"I know the nurses would have liked things to be different...but..." "It was such a pity, the nurses did everything so well..."

The need for conformity to the rules of the organisation on the one hand; and the need to respond to the obvious distress of child and parent on the other presented the nursing staff with a difficult dilemma. This sensitive issue will be discussed in the context of the relationship between research, the development of nursing knowledge, and the implications for nursing practice, later in this chapter.

Phase 3. Home Adjustment and Satisfaction with Care.

3) Will the children who find the experience of hospitalisation and surgery a positive one be more likely to have been prepared for the event, within the experimental treatment condition? and;

4) Will the incidence of post-admission emotional and behaviour problems in the child, be influenced by the nature of preparation for paediatric hospitalisation and surgery?

5) Will parental expressions of satisfaction with preparation, support and care throughout the child's hospital experience, be influenced by the nature of preparation? and, Will parental responses which reflect their perceptions of the total experience be influenced by the approach to preparation?

Hospitalisation-A Positive Experience for the Child?

The literature reviewed in chapter 4 discussed the potential for the hospitalisation experience to be a positive one. Vernon, (1966) and later Prugh (1983) found that some children showed positive changes in behaviour two weeks after hospitalisation. The data reported in this study showed the incidence of positive change to be highest in control group 2, although children within the experimental group were also reported to show positive change. Understanding of the responses required analysis of parental expectations of the child during and following the experience. Few parents reported expecting positive change in their child, while a considerable number, particularly within the experimental group, reported that they expected negative change following transfer home (appendix-table 14). The intervention therefore was considered to influence the outcome in relation to positive change. Consideration was also given to the effect of the additional attention received by control group 2 in relation to that groups high incidence of positive change.

The grounds for assessment of change involved looking to the descriptive accounts of the child's behaviour. It is important to recall that the parents' accounts were retrospective appraisals, based on the knowledge of the child's behaviour before the treatments and on a knowledge of the child's adjustment during and immediately after hospitalisation. Reports from the treatment group who noted positive change (n=9) described the effect of the experience as having had a 'maturing' influence on the child (10:12). The treatment group reported physical change independently of psychological adjustment and change. The reports from the second control group indicated that the parent was assessing physical as well as behavioural criteria in their evaluations of positive change. Control group 2 tended to link physical recovery with reports of positive change in an inverse

relationship. That is; the child who was not fully recovered was reported as showing either no positive change or overt negative changes. Conversely, the child who had recovered well was more likely to be judged to show positive change.

Post-Hospital Emotional and Behaviour Problems.

Reference to the quantitative data (table 5) while showing no statistical differences, showed a distribution which suggested that the experimental preparation group fared 'better' than the control groups. A different perspective however, was offered by the parent in their open responses on the post-hospital questionnaire. Interpretation of the qualitative data highlighted the concerns felt by the parent as the child was perceived to be experiencing some difficulty two weeks after transfer home (10:12). It was suggested that the expectations of the parents within the treatment group prepared them for a period of adjustment following the child's hospital stay. The influence of the experimental approach to preparation was seen in this groups expectations. These expectations were based on an appreciation of the reality of the effect of the admission, surgery and related care on the child. It was also suggested by the analysis of parent's responses that the expectation of negative change coloured parental interpretation of actual behaviours observed in the context of the child recovering at home in the immediate post-hospital period. Review of the behaviours reported by the parent (10:7) support the interpretation of mothers attempts to over-compensate for the the role she perceived herself to have had in the child's hospitalisation, by viewing any alteration in behaviour as negative and thus emphasising the need for mother to be particularly solicitous and tolerant. The data which supports this interpretation was seen to emphasise the child's vulnerability and justify the mothers indulgence in the post-hospital phase of recovery. Examples of responses were; *"He is such a little boy, he can't understand why he is still feeling so poorly"* or *"It's not surprising that s/he is still having a bit of bother, after all most adults would be, after going through all that"* *"He needs such a lot of my attention, I think he deserves it after what he has been through"*

The data above were interpreted in the light of the natural protective role of the mother in the post-hospital period. It was also suggested that the responses indicated the mothers need to redress the balance which many mothers perceived to have been distorted by the delegation of care to the professionals during the child's hospital admission.

Attention now turns to a discussion of the responses which indicate parental satisfaction

with care received throughout the process of the child's hospital care.

Satisfaction with Care.

Discussion of satisfaction, which is based on parental reports, will follow the child and parent through the pre-admission, in-hospital and post-hospital phases. The problems attending the definition of satisfaction and its measurement are addressed in chapter 5 and 11.

Satisfaction with pre-admission care.

The treatment group unanimously reported complete satisfaction with the care received before the child entered hospital. All parents used the post-hospital questionnaire constructively and comment on aspects of the preparation they felt particularly happy with. Important points were also raised about how the preparation programme could be improved. These valuable insights will be discussed in a later section when the experimental treatment is evaluated. A recurring caveat to these reports of satisfaction was the conduct and outcome of the initial consultation. This important issue was reviewed earlier in this chapter.

The control groups expressed strongly phrased feelings of dissatisfaction with pre-admission care (p292). The tendency of the parent to distance themselves from direct criticism of the staff and to prefer instead to target the 'system' was a frequently encountered finding. Interpretation of the data showed the preparation, support and information received by the control groups to be quite inadequate. The control groups therefore entered hospital on the day of the child's admission unprepared for the events. The staff were then given the task of preparing the majority of families for admission and surgery immediately prior to the events. Reference has already been made to the deficiencies of this approach in relation to an understanding of coping theory. The analysis has shown that parents who were unhappy about the preparation received, reached the stage of the child's admission inadequately informed (p 270). The parents were also uncommitted to the procedures, and subsequently experienced anxiety which was less focused and controlled than that experienced by the experimental group. The suggestions made by the parents within this group in relation to preparation, will also be reviewed in a later section.

Satisfaction with In-Hospital Care.

The overwhelming message to emerge from the reports of satisfaction was a positive one and this finding requires to be emphasised and shared, particularly with the staff responsible for delivering the care. Given the important caveats of the clinic consultation and the absence of parents during maximum stress points, parental responses signalled a high level of satisfaction with care received. The manner in which nursing care was delivered to the child and the level of support given to the mother during the child's stay in the ward was identified by many mothers as being beyond their expectations or, similarly, a high quality of care delivered "by nurses who cared". Mothers made insightful comments which indicated the ability of the nursing staff to maximise parental competence and involve the mother at all levels of the child's care, within their freedom to do so. (p302). In addition, responses indicated the nurses ability to relate to the cognitive and emotional development of each child when compiling a care plan for the individual. Although many mothers attempted in the post-hospital questionnaires, to distance themselves from open and direct criticism of the nurse's role or the manner in which that role was carried out, a large number of mothers did express dismay that the two main areas of concern (clinic consultation and parental withdrawal during stress points) were accepted by the otherwise "very caring and conscientious" nursing staff to be acceptable practice in a Sick Children's Hospital(p 304). Hall, (1987) reminds us that it is "a form of professional incompetence not to question existing practice" (p.729). This is particularly so when that existing practice clearly causes distress and is the source of some dissatisfaction with care. In directly addressing the question why are mother's asked by the staff to leave the ward before the child's transfer to theatre? A close knowledge of the manner in which the ward functions on operating days is helpful. Understanding then led the writer to two avenues of interpretation of ward policy. The first was the perceived effect continued parental presence is expected to have on the smooth running of the operating lists. Reference to the comments made by the consultant anaesthetist informed this issue (p 237). The second important issue related to the level of legitimate authority which the nurses perceived themselves to have in the situation, and to what extent their knowledge of the effect of an unpopular practice was able to change that practice. These important implications for nursing practice will be addressed in a later section.

The possibility of parents having limited expectations and thereby being delighted with the care they received, since they expected less, was considered. However, as identified by this analysis, the group of parents who were diffident and uncertain went on to express concrete aspects of care they did feel very happy with *as well as aspects of care they felt*

were unacceptable. All families were seen to use the post-hospital questionnaire constructively. Many (78) described, at great length, often using additional notes, the positive as well as the negative aspect of the experience. The impact of the 'relief factor' was seen as an important consideration in satisfaction measures. This influence generally recedes within a few days of the successful outcome of treatment, as the mother is caught up in the reality of the continuing demands of her convalescing child (Meng, 1982).

As Whyte (1989) succinctly states "...evaluation can only take place when goals have been set and their achievement can be discerned". Assessment of the efficacy of the experimental approach to preparation developed for this research can be clearly made from the quantitative and the richer interpretive nature of the qualitative data.

This study clearly showed that parents were able to distinguish between the nature of staff care and the kinds of services offered. Reference was made by many parents to the attitudes and the moral as well as the practical sense of nursing. For example, "now that nurse Karen, she really is a good nurse". In this example, the parent was making a distinction between inter-personal care and technical care since she went on to explain how this nurse kept all the technical aspects of care "in their place" while "knowing exactly how to comfort a crying child without making his mother feel useless" Nurse researchers are charged with the responsibility of providing feedback to the appropriate colleagues. Satisfaction with care during the child's stay in the ward is an important positive outcome of the study, one which requires to be emphasised and shared. In the same way, aspects of care which the parents felt less happy about require to be discussed openly in relation to the research findings.

Satisfaction with Preparation for Transfer Home

Preparation for transfer home was perceived by the mothers variously as a 'final chat before discharge,' or more frequently, 'being asked to wait for the doctors letter before being allowed to go' (Post-hospital questionnaire -open comments). The findings indicate that preparation for transfer home requires to include attention to the need for continued support for parents caring for the child following ENT treatments.

Analysis showed that parents on the whole were unprepared for the demands of the continuing care required by the child on his return home. Interpretation of the data led to an understanding of the interplay between the mother's expectations and the child's actual needs. Important implications for nursing practice to address more closely the effect of inadequate preparation for transfer home were raised by these findings. In particular

reflections on maternal competence and confidence in caring for her child were apparent from mother's responses. *"I can cope with anything as long as she is safely home"* was the symbolic literalism applied to maternal coping at the point of the child's admission (10:6). Understanding stress and coping responses in acute situations leads to the realisation that after the crisis, comes a feeling of overwhelming relief. The parent experienced a very natural feeling of emotional exhaustion, *"feeling drained and completely exhausted by it all"*. It is little wonder that the parent, who returns home with the child, expecting life to gradually return to normal, when presented with the task of continuing to cope with a lethargic irritable child who still requires pain control and much comfort, feels unable to cope.

The home care of the child in the five days or so, after transfer, represents a *continuation* of the stressful experience with important differences. Part of the planning for transfer home is to redress the balance of responsibility for the child's care and return the dominant role of caring to the parent. Some parents clearly perceived the preparation given for this recovery phase to have failed to meet that goal. *"I never thought it would be like this, I am just exhausted, and there is no-one to turn to"*

While it must be stated that parents' feelings of helplessness may have been exaggerated by the physical and emotional strain of the preceding few days, this places a greater emphasis on the preparation for home if the recovery phase is to be manageable within the existing resources of the mother. Hall (1987), identifies the discontinuity between home and the health care setting experienced by the child as he enters hospital. Analysis of this data highlighted the discontinuity experienced by the child as he left hospital and was integrated back into his home environment. To isolate this phase from that of hospital care is to ignore the contribution from in-hospital treatment to post-hospital distress. The end of the hospital stay can easily be seen as the end of the child's distress and parent's anxieties. This serves to perpetuate the institutional boundary. The recovery phase within this particular speciality, is not observed by the hospital staff. Specific post-hospital treatment is minimal; compliance with continued medical treatment is not an issue, and follow-up appointments are not always required. It is postulated that these factors contribute to the relatively 'low key' approach to preparation for transfer home, which encompasses support as well as information. Therefore, the institutional boundary which at the outset of the experience served to minimise the support given to the parents in relation to involvement in the decisions made on behalf of the child, was also perceived by the parent to limit the continued support which they consider to be necessary after the child returns home.

Support emerged as the key mediating variable in the post hospital outcomes as it did in the pre-admission responses. If mothers as the 'unpaid' carers are to continue to play an important role at the interface between hospital and home, then appropriate support and preparation for that role must be forthcoming. It is not enough to rely on the instinctive need of the mother to care for her child, she requires concrete support and help to do so if the emotional cost to the mother is to be kept within control, and the recovery phase of the child is to progress calmly. These issues will be drawn together and addressed within the context of the implications of this research for the development of nursing knowledge, and this will be explored in a later section of the chapter.

In summary, the families who were prepared for admission within the experimental intervention show overall, to have coped more adaptively with the pre-admission phase and the period of the child's in-hospital care. The findings from the post-hospital data further support the value of preparation. Two clear perspectives were offered by the parent. The first was an overall sense of satisfaction with the approach to preparation offered, a unanimous statement of the efficacy of the intervention was offered by all 30 parents. The second perspective highlighted the parents perception of the possible effects of hospitalisation on the child. Implicit in the parents concerns was an awareness of the potential for upset and change in behaviour which spanned the post-hospital period.

Attention now turns to the development of nursing knowledge which has arisen directly from this study.

12 : 3 THE DEVELOPMENT OF NURSING KNOWLEDGE.

This study had its origins firmly grounded in nursing practice. The research was seen to develop from practice and to draw on relevant theories, which served to inform and structure the development of enquiry. The findings have identified key areas which require to be addressed in relation to the development of nursing knowledge and the legitimate authority of the nurse in carrying out her role. This legitimate authority arises directly from clinical expertise and a sound knowledge base and draws upon Benner's (1984) relationship between 'knowledge and knowing'.

Since theory must be appropriate for the human experience (Leventhal, 1990), it can not be universal and deterministic. In addition, to serve the purpose of being an effective tool, theory in the human sciences must take into account human agency and the uniqueness of human relationships.

Analysis of the data harvested during this study strongly supported the value of the conceptual framework which informed the development of the study. That is; the stress and coping paradigm (Lazarus and Folkman, 1984-a), highlighted the reciprocal

relationship between the conceptual model, and nursing practice. From this paradigm, an alternative model of stress and coping within the paediatric ENT setting has been developed from this analysis. It was accepted at the outset that the model put forward by Lazarus and his colleagues was not intended to specifically address paediatric health care encounters; but rather to present a generic model from which an understanding of the process of stress and coping within any setting may be developed. Theory must begin with human experience, be appropriate to human experience and test its adequacy against human experience. The writer proposes the model of stress and coping within the paediatric ENT (Strachan, 1992) setting as coming some way toward achieving that goal.

Fawcett, (1992) contends that conceptual models inform and transform nursing practice by informing and transforming the ways in which practice is explained and understood. In arguing the necessity of this reciprocal relationship between conceptual models and nursing practice, Fawcett goes on to suggest that such models influence clinical practice by specifying standards for and the purpose of practice; and identifies relevant clinical problems.

In this study, the stress and coping model reflected this authors ideas of the psycho-social care nurses require to consider in relation to the experiences of children and their parents. The reciprocal relationship in this study progressed not from identification of the conceptual model, but from practice which sought description and explanation in the conceptual model, which in turn fed into an interpreted practice within the real world of parents and children in hospital. The result was the development of a new approach to conceptualising stress and coping within the context of planned paediatric ENT surgery.

The danger that some extant conceptual models of nursing are held by some nurses as ideologies that must not be scrutinised or questioned is raised by Jones (1989).

...The use of conceptual models, tests of their credibility in the real world of clinical practice and subsequent refinement or elimination of the model are mandatory, if nursing is to survive as a distinct professional discipline and if nurses are to continue to have the right to care for people. (p.22)

It is the contention of the writer that an equally important caveat in the use of conceptual models in nursing must also be attention to the degree of 'fit' between the model and the needs of the individual whose care needs are clarified by appropriate use of the model by the nurse.

The model developed directly from analysis of the data in this study was seen to articulate the overt and subtle aspects of the respondents reality in relation to the coping strategies and what influenced them.

Stress and Coping Paradigm . Influence of the model on Parents of Children undergoing ENT treatments. (Strachan , 1992)

Figure 6.. Influence during the pre-admission phase.

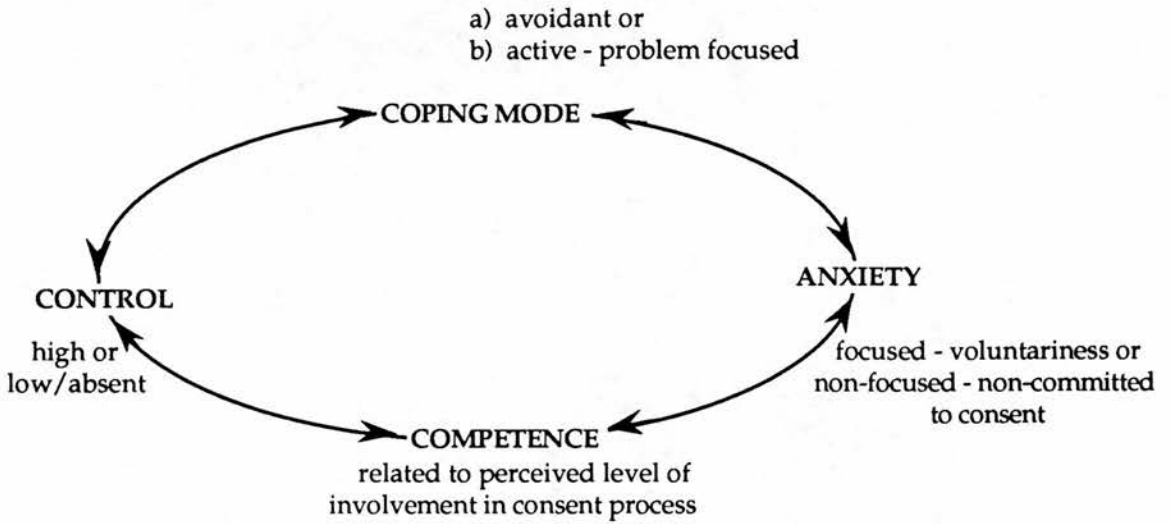
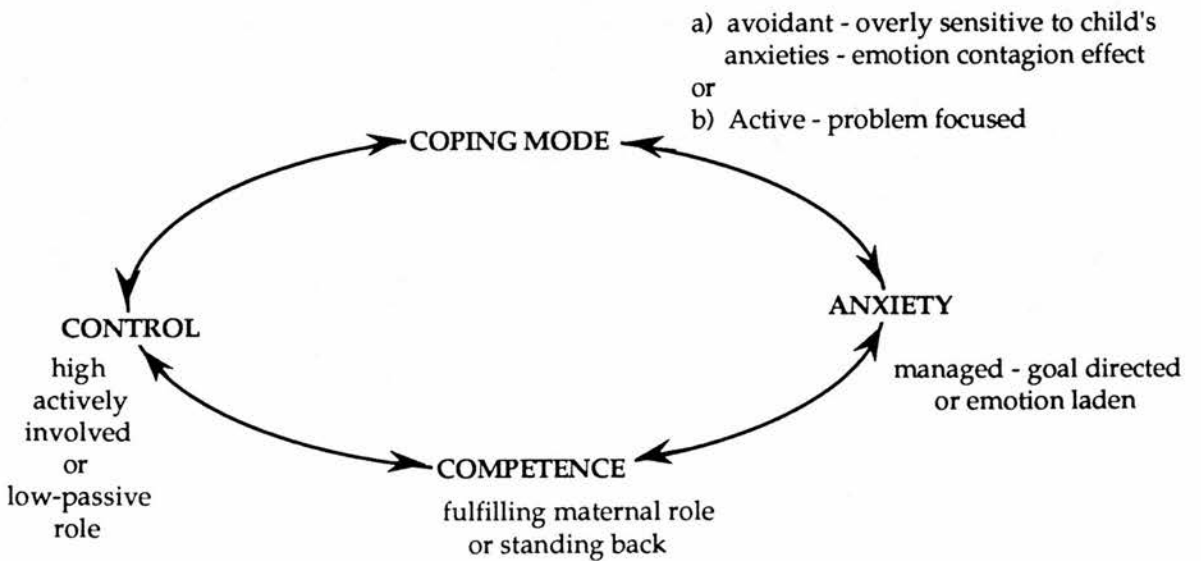


Figure 7.. During the Child's Hospital Treatments.



The implications of this model for a fresh conceptualisation of stress and coping within paediatric ENT settings are now put forward.

Discussion.

Figure 6 informs an understanding of the mothers coping before admission of her child. The data showed the patterns of coping adopted to be influenced by, and in turn to influence, the levels of anxiety to which the mother was exposed during the anticipatory phase of the experience. The anxiety was further found to be influenced by the degree of control the mother perceived herself to have over the initial decision to accept surgical intervention on behalf of the child. This bi-directional relationship was seen as mothers who reported being committed to, or having reached the stage of voluntariness to the treatment plan, were found to manage their anxiety. In turn, this anxiety was focused on the specific nature of the surgery and subsequent recovery of the child. Conversely, mothers who perceived their control over the initial treatment decision to be low or absent, reported that they were unaware of being offered a choice in the treatment options, therefore considered that they had no influence in the initial decision making process. The anxiety reported by this latter group of mothers (all of whom were in the control groups), was found to be out of control, and directed towards uncertainty and lack of confidence in the 'passive' decisions made. Similarly, the degree of competence in caring for the child while in the ward was predicted by the mother to be low. A bi-directional relationship was also found to exist between this lack of confidence in fulfilling the parental role during the child's time in the ward, the degree of perceived control the mother felt over the events and the subsequent level of anxiety experienced.

In summary, the coping mode adopted, whether avoidant or active-problem focused was influenced by and in turn influenced, the perceptions of anxiety. This anxiety was seen to be determined in part, by the degree of control over the events-this perceived level of control fed back into the coping mode adopted and subsequently the anxiety experienced. While addressing coping as a dynamic process, the nature of mothers coping with the ENT surgical treatments of their children point to the presence of a positive or negative cyclical phenomenon. This negative coping was found in the study to lead to a reciprocal relationship between avoidant or non-channelled coping efforts by the mother; high expressed anxiety; low levels of perceived competence and lack of control.

The positive cycle of events was seen in the mothers who adopted an active problem focused coping mode. This active coping was either enhanced or made possible by

perceptions of control over the events in which the mother felt she had reached the stage of voluntariness in the consent process. Anxiety was managed in this group and directed towards the child's surgery and recovery, rather than towards feelings of uncertainty and lack of commitment to the surgery *per se*. The perceptions of control fed into and enhanced the level of confidence with which the mothers envisaged fulfilling the parenting role during the child's in-hospital care.

Figure 7. depicts the influence of the model on the mother's coping mode during the child's hospital treatments. Emotion contagion as a bi-directional concept is explored as the relationship between the avoidant coping mode, which resulted in the mother being overly sensitive to the child's anxieties, and the association between child and parent anxiety is addressed. The management of anxiety is seen to be goal directed or emotion laden. This patterns feeds back into the coping mode and forward into the manner in which the parent fulfils her role in caring for her child. This caring role emerged as one which was either fulfilled, or one in which the parent was seen to stand back, being uncertain and diffident. The influence of the initial degree of control which the parent perceived herself to have had over the process of the child's admission and subsequent surgery (as explored in figure 6) was found to be related to the anxiety expressed by the mother when assessing the child coping with in-hospital treatments. In addition, mothers who perceived themselves to have had low or no control, reported that they expected their child to be more upset by the events than mothers who had a higher level of control. In effect, the analysis explored the relationship between mothers reports of the child's expected anxiety and personal anxiety reported by the mother. Emotion contagion was seen *not* to operate as a bi-directional concept in this study, that is; from child to mother and mother to child. Rather, the anxiety was seen to reside in the mother, who expected that anxiety to be reflected in her child (chapters 10 and 11). The inter-relationship between coping mode, management of anxiety, maternal competence in the hospital setting and degree of control was interpreted from the responses made by the mothers in the study. It is evident from the interpretations of the responses made by mothers that the issue of personal meaning of the events is a pivotal dimension in their subsequent coping. As has been raised earlier in the discussion, opportunity for reappraisal of the 'significance' of the events was offered to the group who experienced the experimental approach to preparation.

The value of hermeneutic interpretation was seen as insights gained at the clinic consultation phase of the process were found to contribute to and further develop understandings at a later stage in the experience.

The careful critique of the applicability of a conceptual model can only begin when the staff are already 'experts' within a particular field of nursing and can use their skill and expertise to draw from nursing knowledge and human sciences, that which serves to further inform and contribute to an excellence in practice, thus reflecting the dynamic nature of nursing and the rapidly changing needs of the patients and their families. In proposing the utility of the model developed, which has been shown to further inform an understanding of the experiences of children and parents as they prepare to admit and subsequently help care for, their child who is admitted to hospital for elective ENT procedures; the writer is aware of the limitations of any conceptual model applied to inform nursing practice. In particular, it is relevant to recognise the contradiction inherent in proposing a *single* conceptual model to achieve an individual approach to care. It is suggested by the writer, that what can be usefully achieved by the application of the model developed in the analysis, is a framework upon which the responses of children and their parents as they undergo treatments may be understood in relation to their individual needs. In particular, nurses caring for children within an ENT setting, may refer to the model developed from this study, to help plan the pre-hospital and in-hospital care of the family. Awareness of the potential to circumvent the negative aspects of anxiety and maximise the strengths of the children and parents in the stressful encounter, may be enhanced. The integration of other models which reflect specific care needs is clearly also required.

In applying the psychological theory of the stress and coping paradigm to this study, the writer is addressing the need for nursing research to identify the process of coping with health care and provide a conceptual framework which considers the dynamic nature of stress within the medical setting. It is important that nurses know how stress is generated and how coping resources can be enhanced if they are to be influential in mitigating the distress experienced by their patients and their relatives during health care encounters. Many writers have made significant contributions to the nurses knowledge of stress and coping (for example, Bailey and Clarke, 1989, McHaffie, 1991). This study proposes stress and coping as a conceptual model which provides a firm basis for the development of caring within a paediatric setting, since this conceptualisation addresses the crucial nature of the individual within context, an essential pre-requisite to understanding stress and coping responses within the medical setting.

The outlook of Styles (1982) shares common ground with this researcher "Begin with an assumption that whatever nursing is now...we need to and can do more to improve our condition" (p.55).

The primary goal of all health care initiatives is to promote the physical and psychological well-being of the individual and his close family. Benner (1984), describes how nursing knowledge, the 'know how' derived from practice often runs ahead of and challenges the knowledge of scientific theory. Benner further distinguishes sharply between theoretical and practical knowledge. An approach more conducive to the development of nursing knowledge would, it is proposed, be to integrate the theory at the outset to further understand and develop the practice. For example, hermeneutic enquiry makes it possible to begin with interpretations of practical experience and use theoretical explanations to both better understand that experience and to use that understanding to improve practice. In this way the on-going reciprocal relationship of theory to practice; and the reflecting of theory to further develop practice, provides the momentum for nursing practice to move forward towards the goal of excellence.

Practice is never static, it is improved through realising its inherent possibilities, not only in changing its ways for pursuing the good but also by new visions of what constitutes the good of the practice.

The relationship between research and the potential to influence nursing practice is now examined.

12:4 The Relationship between Research , Practice and Education as it relates to the Present Study.

Consideration of three areas of nursing knowledge made explicit by analysis of child and parent responses, will now be discussed in relation to the importance of articulating the close relationship between research, theory and nursing practice in the development of nursing knowledge. These areas identified by the analyses as being of particular concern subsume the key findings of the study, that is, the need for preparation for paediatric hospitalisation per se; the opportunity for the nurse to develop pre-admission care as an integral part of her role; and the importance of the nurse questioning accepted practice in the light of child and parent responses to aspects of care received by them.

The key areas addressed are:

- a) The unique position of the nurse
- b) Fulfilling the legitimate role of the nurse
- c) Listening Sharing and Responding

i) The unique position of the nurse.

Reference has been made (chapter 4) to the unique 'in-between' position of the nurse. This study raises important questions in relation to how the nurse functions within that unique position, particularly in relation to preparation of the child and his family for paediatric hospitalisation. If parents are to be assisted by the nurse to authentically exercise their freedom of determination (Gadow, 1980), then the very manner in which the process of preparation is presently carried out requires to be brought under scrutiny. Nursing involves helping persons become clear about what they want or feel they require to do, by assisting them to discern and clarify their values in the situation. On the basis of that self-examination, the individual may reach decisions which express their reaffirmed, perhaps recreated, complex values. In this way, nursing may become closer to determining the personal meaning which the experience has for that individual child and parent.

Concern was expressed at the outset of this study for the present trend in relation to the direction in which priorities are set in terms of cost-containment and maximising throughput of children requiring ENT procedures. The nurse in her unique 'in-between' position has the professional obligation and right to challenge such decisions, based on her awareness of the aims of health care provision in promoting the well-being of the patient and his family. The efficacy of the experimental approach to preparation has been upheld by the findings addressed in the analyses. The influence of research studies on nursing practice are more likely to be positive if the intervention is seen to be implementable within existing resources and the staff have been involved in the development of such an intervention. Both criteria have been met in this study (chapter 6). The practices of medicine and nursing are forms of inter-personal praxis which have a shared common goal. However, even when the moral sense of caring is dominant, that is promoting the patient's well being, the doctor and nurse may have different immediate aims. Bishop and Scudder (1990) make the pertinent point that harmonious collaboration between professionals engaged in health care delivery does not necessarily naturally evolve from shared long term goals. The professionals may challenge a system which appears to place a greater priority on political/economic considerations than is perceived to be placed on the legitimate rights of the patient and his family for autonomy; and a quality of care which meets their expectations and also those of the staff who deliver the care. 'Putting Patients First' (Secretaries of State, 1989) is a laudable statement, but is meaningless in the light of current cost containment, maximising throughput and allocation of resources which may serve the purpose of administrative efficiency, but achieves little in relation to the goals of the staff who strive for an excellence in clinical care; care which

the recipients have a right to expect. It is within a relatively turbulent environment, of rapidly changing health care priorities, that nursing practice must take up the challenge for change. Change which reflects the patient and parent's right to freedom of determination within the health care system which purports to serve them. A problem occurs when analysis of the nursing paradigm and the disciplines philosophy reveal basic incongruities, paradoxes and conflicting ideologies. If a paradigm guides and perpetuates practice, it is essential to analyse where it takes the profession in relation to the professionals stated beliefs and values.

This study highlights the value of the stress and coping paradigm as a conceptual signpost which nurses may apply when seeking an understanding of the responses of children and their parents from the earliest contact with the outpatient clinic through to the preparation for transfer home and continuing care. The model developed directly from the study addresses the close inter-relationship between active coping during the initial phase of the process, and subsequent control which influences anxiety throughout the process. The onus on the nurse to address the need for a re-appraisal of the philosophy of preparation is therefore a major implication of the findings. The debate which centres on nursing autonomy is an important consideration when looking at the role of the nurse in preparation initiatives.

Nursing Autonomy or legitimate authority

The role of the nurse as an autonomous professional within the caring team, despite the clear contradictions, has been put forward as a viable goal of nursing *per se*. Haworth, (1986) describes "competence as the foundation for autonomy" (p.2). the implication being that the competent nurse is also autonomous. It is the writers view, a view shared by some other writers (for example, Bishop and Scudder, 1990), that within the health care team, the nurse functions within her unique 'in-between' position. This position enables her legitimate professional authority to grow from within her practice, that is with her developing skill, knowledge and experience. To suggest that the nurse can be autonomous is, in the writers view, a contradiction. The health care team operate as a functioning unit each with their own unique contribution to foster the physical and emotional well-being of the patient. While it is the case that some members of the team have more legitimate authority than others, no-one can have complete autonomy. The legitimate authority of the nurse does not therefore emanate from any external bureaucratic structure or rules which regulate the profession. To suggest that it is not possible to have legitimate authority within nursing without being afforded autonomy, is to misdirect the major moral

thrust of nursing. Nurses do not have autonomy in the same way as doctors, they do have their own kind of authority which when exercised within their 'in-between' position, may reform practice thus making a direct contribution to the practical and moral development of nursing.

Englehardt (1985) describes the 'in-between' situation as one in which the nurse is 'caught' - thus implying powerlessness and ambiguity. However, the writer would suggest that the unique position of the nurse is a position of strength. For example, being 'in-between' the doctor, patient and his relatives and the hospital administration, often places the nurse strategically where alternative approaches to care can be promoted, thus fostering the good of the patient. For example, analysis highlighted the value of preparation for paediatric hospitalisation, to both child and parent (11:5). The nurse, from within her 'in-between' position may identify preparation as an aspect of family care which requires a greater commitment. In making the commitment, nursing may then progress to a real involvement in pre-admission care, thus encompassing the progress toward family care which is implicit within the philosophy of paediatric care adopted by the staff. The legitimate authority of the nurse is seen as a responding to and actively striving to change, aspects of the child and parent experience which are identified as falling short of the stated goal of health care, that is an excellence in care.

Health care is a communal enterprise, when we talk of autonomy in health care settings, the real issue requires to focus on maximising the autonomy of the patient and in the case of paediatrics, his parents. Decisions as contributive efforts are reached from different vantage points. When these perspectives function as they should, in concert, they all contribute to the moral sense of practice by fostering the well-being of the patients. However, when the professional sense replaces the moral sense of caring, Bishop and Scudder (1990) argue that the well being of the patient is no longer the primary goal of health care.

ii) Fulfilling the Legitimate Role of the Nurse.

This study has raised important professional issues of some concern. In particular, the absence of appropriate information and support at the initial clinic consultation, the lack of preparation programmes to all families, and the existence of aspects of ward policy which were perceived by the parents to increase child and parent anxiety at times of heightened stress, were identified by the parent's as being key concerns (p 304). The value of the discriminating approach to preparation studied in this investigation has been upheld by the findings.

Whyte (1989) in her study of families of children with cystic fibrosis proposed the extended role of the nurse in relation to the continuing support and care required by these families. Whyte went on to offer the caveat that the extended role of the nurse has been viewed as nurse taking up a limb of the medical role in becoming more oriented toward the technical care of the patient. The writer would propose that rather than view the support during the pre-admission and recovery phase of the patient and his family as an extended role of the nurse, it should be viewed rather as that of the legitimate role of the nurse in exercising her commitment to family care. In effect, this study identifies the need for the nurse's role to form a *coping bridge* between the initial clinic consultation and subsequent admission to hospital. Addressing coping theory within this framework the role of the nurse is viewed as a way of helping the parent and child to mobilise their own coping resources and thus come to address the issues in a realistic and informed manner. The presence of social support and the quality of professional care (which includes preparation) have been found to have a significant effect on parents perceptions of anxiety before the event and their reports of satisfaction with care after the experience (11:3 and 11:5). Nurses therefore have the potential to maximise parental autonomy in the situation and thus contribute to the coping efforts of the parents.

In this way, proxy consent would become a process, as the nurse, having established the coping bridge, set up a link between the parent and the support which the professionals can offer. In so doing the nurse is exercising her legitimate authority and fulfilling the moral and practical sense of caring.

iii) Listening Sharing and Responding

The moral sense in health care requires promoting physical and psychological well-being of patients in a given health care context. This context requires that decisions be made co-operatively by physicians, patients and nurse working in a setting conducive to effective health care. From within the moral sense of practice, the first responsibility of the nurse becomes excellent practice. Moral issues arise from within health care practice when the fulfilment of the moral sense is inhibited. This situation was apparent in this study as parents shared their feelings of confusion, dismay and extreme anxiety when asked by the staff to leave the ward at a time when the parent perceived their child's need to be greatest (p304-6). The nursing staff were seen by the parents to listen to their concerns and in many instances were also considered to be empathetic to their situation. The data suggested that the nursing staff were aware of the significance of asking parents to comply with ward policy (11:5). However, the nursing staff were also seen to be unable to respond in a manner which would have mitigated the distress of the parent and in the parents' view, that of the child also. Co-operative use of legitimate authority is necessary in

making decisions that foster the well-being of the patient and his parents. In making these decisions, the idea of compromise, rather than being interpreted as a negative concept, becomes a positive attempt at determining sound practice which maximises patient well-being.

The writer suggests that within the concept of caring, the nurse in this situation *was* in a position to challenge accepted practice on the basis of the effect that practice was seen to have on the emotional well-being of the family (personal communication with senior nursing staff on the ward). In utilising the strength of her 'in-between' situation, the nurse could respond to the needs of the family. Failure to do so was interpreted (by the parents) as rigid adherence to existing practice in an effort to maximise the efficient running of the ward.

While listening and sharing are important facets of the caring approach to practice, fostering change can only be brought about by identification of an aspect of practice which is known to cause distress or dissatisfaction; and a sensitive responding on the part of the team, to effect change. When the desire to maintain a stable predictable nursing practice inhibits attempts to reform practice by realising the potential for good inherent in it, seeking refuge in the 'ward policy-doctor prefers it this way' adage becomes unacceptable.

It is apparent from analysis of the data in this study that each practical problem raises broader philosophical issues. The study has shown the potential for fostering change from within the unique position of the nurse. That is; within a caring approach to nursing practice, and with a sound knowledge base, the nurse may become the agent of change which reflects the right of the patient to assert his autonomy as the recipient of that health care. Nurses find fulfilment when nursing competence in a practice achieves the concrete good for the patient in a way which confirms the worth of that practice and of the nurse herself. While this study did not set out to examine the stress to which the nurse is exposed on a day to day basis (this is comprehensively addressed by Bailey and Clarke, 1989) situations in which the nurse perceives herself to have failed to meet the needs of the hospitalised family, have the potential to engender stress.

Reference to the post-outcome questionnaires supports the success of the nursing act in terms of most aspects of care received by the child and his family during the experience. However, the need for current practice to be challenged in relation to the two key issues of discontent, that is the clinic consultation and subsequent support; and the policy of asking parents to leave the ward when they would rather stay with their child, places a moral obligation on the nursing staff to re-address these areas on the grounds of the rationale presented in this discussion. As Gadamer and McIntyre (1984) point out, competency is what excellent nurses do, virtue what nurses must be in order to do what they do.

For nursing practice to progress, it must be studied in ways appropriate to the practice and the context. Improvement in nursing practice does not come from philosophers or other outside 'experts' prescribing new practice, but from nurses themselves, actually recognising and realising the possibilities inherent in their practice. In this way nurses direct the development of their own profession and contribute with others in health care provision to a living, dynamic practice directed toward the future.

Having discussed the salient findings from this investigation and demonstrated the relevance of this research to nursing practice and indicated the implications for change, a critical review of the experimental intervention will be presented prior to addressing the recommendations arising from this study.

12:5 An Assessment of the Experimental Intervention

A comprehensive discussion of the development of the discriminating approach to preparation which was developed by the staff nurses and the researcher may be referred to in chapter 6. The perspective of the family, the staff and that of the organisation will be reviewed. Anecdotal accounts of the staff perspective and that of the organisation are included, since it was not the intention of the study to secure and analyse data from these sources. The information presented was gathered during informal discussions, some of which were tape recorded.

The Parent and Child Perspective

Assessing the efficacy of the approach was reviewed throughout the analyses (chapters 10 and 11). It was apparent that all parents (n=30) prepared within the treatment condition, perceived the intervention to be beneficial to the child and invaluable to the parent (11:6).

Similarly, the 'blind' observer ratings of the child's responses to maximum stress points during the experience showed the children within the treatment group to be less distressed and more co-operative with most of the procedures. This was seen to apply to children across both age ranges.

Home adjustment presented a variable response. While the quantitative data showed the experimental group to be less distressed and to adjust 'better' to home, parental reports suggested that some children within the treatment group were upset by the experience. (10:9). A rationale for this finding was presented in an earlier section of this chapter.

All parents within the experimental group reported that the child had benefited overall from the experimental preparation. A further important point in the assessment of the efficacy of the intervention is that of the responses of the parent's within the control groups. A number identified lack of preparation as a key cause for concern and made suggestions for the development of an on-going programme (11:5).

Feedback from Staff

The following information was reported to the researcher during informal discussions both during and after the period of data collection.

Formative assessment of the experimental intervention was undertaken throughout the period of data collection. This was important in a clinical nursing study, since the researcher must be ready to respond to sudden changes in staffing and other logistical problems. In the event, the practical conduct of the intervention progressed smoothly. Staff holidays were accounted for at the outset of the planning stage and adequate staff numbers were prepared for the role. Feedback from the staff support the efficacy of the intervention in terms of the satisfaction felt by the nurses as they prepared children for hospital. The initial contact enjoyed with the children and their parents was seen to contribute to the development of primary nursing for that group. Reports from nurse observers on the manifest upset and co-operation scales recorded during the period of treatments supported the value of the preparation in terms of securing a calm and co-operative child at maximum stress point of the experience.

Involvement by the qualified staff during the preliminary stages of the development of the intervention, achieved the goal of researcher and staff working together towards an intervention which was implementable by the staff within the context of existing resources. This was a key pre-requisite, since in the light of the current funding within the health service and the need for nursing research to be cost effective, the possibility of such an intervention receiving additional funding (for example, additional staff or expensive intervention measures, such as puppet therapy) was accepted as slender.

In addition, the researcher addressed the possibility of the research initiative being continued after the period of data collection and analysis; if the findings upheld the value of the intervention. Therefore, the need for preparation approaches which could routinely be carried out by the ward staff was considered by the researcher to be an important condition at the outset.

The following quote is reported verbatim since it is considered to crystallise the staff attitude to the research initiative at the end of the period of data collection.

"My first impression of this research, when things were being discussed was oh no! this is not for me, I want to stay out of this...I thought another 'airy fairy' study with no real relevance to what we were doing in the ward. However, (as you know), I became very enthusiastic when I realised that we were involved in setting up this preparation which would influence how children and their parents are prepared for hospital. The fact that it was based on what we could actually and realistically do was, I think, the main point in it's success. I hope it can continue now we know it can be done and the parent's and children say how much they appreciate it." (Transcribed form informal discussions with the staff nurses at the end of the field work)

Having addressed the strengths of the intervention as perceived by the child, parents and staff, the limitations also require to be considered.

The weakness of the preparation approach lies mainly in the need for the intervention to take place at a prescribed time each week, therefore little flexibility was possible. This was necessary in view of the operating load of the specialist area and the day chosen was the only day when a theatre list was not in progress. While all who were invited to attend, did so, many (n=16) parents made the comment that they would have preferred a choice of days. In attempting to pre-empt the practical problems which parents may encounter, the planning stages of the intervention also made provision for younger siblings (the hospital play-centre was made available during the preparation afternoon). In addition, the time was scheduled for after school, therefore it did not interfere with the school day.

The few parents who reported that they would have preferred to have more time with the staff nurse during the counselling session made the important point that to be effective, this approach to preparation should not be rushed. The staff were of the view that adequate time was given to each parent, but that some seemed to 'be reluctant to end the discussion' (direct quote from staff nurse involved in the intervention). A balance does require to be drawn however between the staff and parent perspective. The willingness of the staff to take time to alleviate the anxieties of the parent in the situation should not, it is realised be dominated by temporal concerns. The real constraints on the professionals time does require to be considered. The staff nurses who conducted the intervention were experienced Sick Children's nurses who had also undergone 'professional studies' modules, which included a counselling component. This important issue requires to be re-considered in the light of parent and staff comments. This can be achieved most effectively during discussion of the findings of this research with clinical colleagues.

The input by the medical staff, that is recording manifest upset and co-operation scales presented no problems, although the rotation of junior medical staff required the researcher to be available to explain the procedure and to monitor inter-observer checks on two occasions during data collection. The consultant anaesthetists reported that they were able to assess the child's induction response and record it, with no inconvenience, since they routinely record the nature of anaesthesia for each child.

The Organisation.

The key point which was raised by the experimental intervention was that of resources. The Director of Nursing Services was involved in all preliminary discussions and was reassured that the intervention would not make 'exceptional demands' upon the nurses time. Careful definition of what constituted such demands were openly discussed with the ward staff, the Director of Nursing and the researcher (chapter 6). Feedback confirmed the efficiency of the intervention in terms of appropriate and constructive use of the nurses time. No additional staffing was made available, although the points raised by the parents in relation to additional time being found (above), suggests that a further qualified nurse would have been able to share the load and increase the time spent with each family. These points will be put to the senior nursing staff when the findings are discussed.

The recommendations for practice are now reviewed.

12:6 RECOMMENDATIONS.

The recommendations arising from the above review of the relevance of this research to nursing practice are presented. The implications of this study for a re-appraisal of current policy in relation to preparation for paediatric hospitalisation is of central concern and underpins the main structure of this study. As discussed in the planning stages of the intervention (chapter 6) and confirmed by the feedback from staff, the changes suggested in this section are able to be made without major injection of additional resources. Rather, the emphasis is on maximising the use of resources already present. With commitment and further appraisal of the rights of children and their parents to preparation for planned admission to hospital, the achievement of the goal of mitigating the stress inherent in paediatric hospitalisation may be met.

Recommendations for nursing practice.

i) In relation to the clinic consultation. - Fulfilment of a Legitimate Nursing Role.

The nurse is in an excellent position to apply her knowledge of child development and of stress and coping within the medical setting, to an understanding of the support and information parents and their children require before they enter hospital for treatments. The data lend support to the role of the nurse within the initial clinic consultation (12:2). The new conceptual model developed from this analysis (Strachan, 1992), highlights the importance of providing adequate support and information to the parents at the referral stage of the process (p 339), not only in relation to the pre-admission phase but also throughout the child's experience . Recommendations arising from this finding are:-

1. The presence of an experienced nurse at all ENT clinics and during all phases of the consultation; this would encourage the co-operative approach required to ensure family centred consultations. The nurse may then begin to establish a link between the parent/child and hospital. Since the waiting list within the health board area studied is currently 6 months (LHB, 1992), this bridge between the initial contact, when the decision to select a particular treatment plan is made, and eventual admission, seems an important link in relation to the coping efforts of the parents and children before and during the treatments.

2. Provision also requires to be made at the clinic for a quiet time, a time of reflection on the personal meaning of the consultation, with the opportunity for reappraisal based on further information and support from the staff (chapter 11:5).

3. The data also signals the importance of addressing the manner in which the clinics are conducted to achieve a facilitative environment conducive to listening and sharing.

The time spent by doctors on the initial consultation requires to address the unique nature of that 'routine' consultation to the parent and to create an enabling environment, one which may become conducive to parental involvement in decision making. While this need not necessarily increase clinic time, parents identified as being particularly anxious may then be counselled at the time of the clinic appointment by the nurse specialist. The need for such clinics to become more child and parent oriented is raised by this study.

ii) Recommendations for in-hospital care. - Acting in the best interests of the Child and Parent.

1. While it is important to address the structural limitations and absence of material

resources which clearly impinge on the policy to ask parents to leave the ward when they would prefer to stay (p 304), it is equally important to ask if the policy is actually one which reflects the best interests of the patients or rather, one which reflects the need for the smooth running of the organisation. The commitment to parental involvement can not be selectively defined by nurses, but should be negotiated with and reflect the values of the parent. The data strongly supports the need for nursing staff to re-appraise their perceptions of the role of the mother during the 'acute' phase of the child's in-hospital care .

2. Aspects of that care were also identified as being problematic. The approach toward post-operative eating and drinking within the ENT unit requires to be reassessed (10:8). A less threatening approach seems to be required (10:9).

3. The facilities provided for the mother during her time in the ward were also identified as falling short of expectation (p 306). The availability of a quiet room, which should be non-smoking and the presence of facilities for mothers who are not resident, to 'freshen up' and obtain some refreshment during the long and emotionally taxing days while their child is in the ward is required.

iii) Recommendations for Preparation for Transfer Home.

1. The role of the nurse as a supportive resource has been addressed throughout this discussion. The data which reported the parent's coping with the child's continuing care described confusion and misconceptions held by some parents in relation to the specific nature of post ENT surgical care (p 307).

Parents require re-reinforcement of the advice they have been given. Printed leaflets often do not address the specific concerns. The availability of the coping bridge referred to in relation to the initial preparation (11:3), requires to extend to the recovery phase. This also addresses the legitimate fulfilment of the nurses role at the conclusion of the coping process.

iv) Recommendations for the Preparation of Children and their Parents for Paediatric Hospitalisation.

The findings support the efficacy of the approach to preparation developed for and tested in this study. The discriminating approach was found to address the more subtle and discrete elements of child and parent preparation. In particular, attention to the individual child and parent proved to be an effective way for the staff to begin to develop a relationship with the family prior to the child's admission. This approach was

perceived by the staff to be more fulfilling in terms of the satisfaction with care experienced by the nurse herself. In addition, the individual nature of the preparation ensured that information given and support offered, were entirely appropriate to the child's developmental level as well as to the mother's counselling needs. The aspects most strongly favoured by the parents were the following:- The presence of an experienced staff nurse who had a wide knowledge of the specialist area and was able to spend time with each family was seen by the parent to provide a facilitative and caring approach to preparation. Mothers commented on their ability to use the time to explore their own feelings and misconceptions about the forthcoming surgery for their child. A further important benefit was that of the child being able to identify and locate the people and events in terms of the reality of paediatric ENT care. Parents reported the value of the approach in terms of what the child understood after preparation, compared with his appreciation of the events before the intervention. Further indications of the efficacy of the intervention were considered to be the practical aspects of the events. Those practical aspects, although clearly stated on the standard information leaflets sent out to all families, required clarification during the experimental preparation.

The findings highlight the need to establish a commitment to more discriminating preparation initiatives, which can address the needs of the individual family. Preparation requires to become an integral part of the care received by the child and his parents as they prepare to admit their child to hospital. Analysis of data from the control groups indicated the limitations of the standard approach to preparation currently employed.

This study, in addressing the current climate in health care funding, set out with the important premise that the preparation programme developed for this research should be implementable by the staff already responsible for child and family care (chapter 6:2). This goal was achieved. Feedback from the staff supported the view that the programme was implemented with no additional resources being allocated to the ward staff (p348). A key to the success of this programme is that of asking the staff to state the goals of such preparation in conjunction with the child and parent. Only then can useful evaluation take place. Analysis of the data supported the efficacy of the preparation perceived by the parents in the experimental group.

12:7 Generalisibility of the study findings to other paediatric settings.

Many of the findings may be applicable to other paediatric ENT situations. In particular, the psycho-social care of children in hospital is considered not to be specific only to this study. In addition, the importance of a re-appraisal of attitudes currently held by the

professionals to the initial clinic consultation appears to be a necessary pre-requisite to effective preparation of child and parent. A key point is that the perception of the ENT procedure as 'routine' paediatric surgery presents an inherent contradiction. Acceptance of this point may alert clinic staff to the need to be more sensitive to the needs of the individual family.

The need for preparation programmes *per se* has been well documented as being of value in preparing children for the stress inherent in hospitalisation (Azarnoff, 1982, 1985). The findings from this study support this initial premise and go on to identify a more discriminating approach which incorporates the specific needs of the individual family. The findings which relate to the approach to preparation could be applicable to the general paediatric population. Clearly replication studies would require to address the specific context as well as the nature of the objective stress. The implications for the preparation of nurse learners for the paediatric 'branch programme' (UKCC,1986), in relation to the psycho-social care of children, are considered to be applicable to all nurses preparing to care for children in hospital.

12:8 Directions for further Research.

The study of children's responses in the medical setting presents a very rich, exciting and rewarding arena in which the psycho-social care of the child may be studied. Reference has been made for the need to directly ask children themselves about their experiences. Clearly, researchers who select to interview children of varying ages require to address the key issues of the availability of sensitive and reliable instruments as well as the additional resources such research would undoubtedly generate. Further study, using a qualitative method would tap this area and identify important aspects of the child's experience which may influence the development of preparation programmes. For example, the value of the discriminating approach to preparation studied in this intervention is apparent as the parent's respond on behalf of their child. The child's perspective, which would indicate not only his present conceptions of medical treatment *per se*, but also his developmental stage, which may not necessarily be synonymous with his chronological age, would provide the paediatric nurse with an invaluable guide to the development of an individual approach to preparation and subsequent in-hospital care. In the light of the positive responses of the younger children to the experimental intervention and the nature of the questions asked by them as they anticipated admission, the value of preparation of non-hospitalised young children represents an important, hitherto under-researched area of preventative psycho-social care.

A further important area of study which was not addressed in this investigation is that of the perspective of the nurses. The study set out with the goal of assessing the efficacy of an experimental approach to preparation of child and parent. In the light of the positive feedback from the staff in response to the intervention, further study could examine the relationship between such initiatives and the professional and personal fulfilment experienced by staff involved in preparation. The potential to develop further, the relationship between role satisfaction and work stress, may be raised by investigation of this aspect of the nursing role.

12:9 Plans for the dissemination of the research findings.

The writer views the research process as incomplete until the findings of the study have been disseminated to colleagues and the opportunity for critical appraisal and stimulation of other research initiative presented, for example, those suggested in 12:8 above.

Feedback to the staff directly involved in the study was on-going and a discussion with the senior nursing staff took place when analysis was completed. Plans for a workshop venue as an appropriate forum in which to address the present findings are being considered. In addition, the preparation of articles for professional journals is underway. The teaching and research commitment of the writer will also serve as an important vehicle for dissemination of the findings.

12:10 Limitations of the Study.

In considering the limitations of the present study further areas for future research which are seen to contribute to the discussion above (12:8) are also indicated.

Parental Perceptions of Child Responses

A fundamental point in the approach to data collection in this study was the reliance on the parent's perceptions of their child's responses throughout the event. While the writer supports the position of Harris (1979) "...if you want to know how children feel about an experience, you must ask them" (p.144), this approach was inappropriate in this study for two reasons. The first is the requirements of the experimental design chosen to test the efficacy of the intervention. This necessitated a minimum sample size (90). This modest sample size in quantitative terms, was considered by the writer to be cumbersome in qualitative terms and therefore precluded interviews with the children. These interviews would have been necessary both before and following the experience. The

second important reason for relying on parent's perceptions of child responses was the wide age range studied. This age range (3-7 years) reflects the most common age at which children enter hospital and in particular the most prevalent stage at which children encounter ENT problems. The methodological difficulties posed by developing instruments which would be useful across such a sensitive and rapidly changing time of emotional and cognitive development were not resolved in this study. The use of nurse observers and the steps taken to control for observer bias is seen as an attempt to balance the source of child responses. The point made by Thompson, (1986) in his review of the current literature is pertinent here. That is; studies which examine the perspectives of both child and parent are sparse quite simply because the "methodological apparatus has not been sufficiently developed to allow effective study of both complex perspectives within health care settings" (p 86). The responses of the parent are valued in this study and were seen to contribute to a fuller understanding of both parent and child experiences.

The limitations of resources and the wide geographical area represented in the sample required that this study was kept within manageable limits. Therefore research questions which addressed these limitations at the outset were developed.

The Requirements of the Experimental Design.

The need for the experimental design to control for factors which would influence the outcome of the experience, in particular, the nature of the objective stress experienced, necessitated selecting a sample of children who would all undergo elective procedures of a similar nature. The experience of children who are admitted for medical rather than surgical procedures, and for surgical procedures involving more widespread intervention, is therefore not studied. This limitation was identified by Prugh (1983) who made a plea for studies to adopt a "wider diagnostic base" (p187). The problem with this approach, as has been addressed (chapter 8) is that of the personal meaning of the experience to the child and family. Selecting a sample of children with unknown or more serious conditions introduces bias which would render subsequent comparative analysis meaningless.

The Pre-Hospital Personality of the Parents.

While data relating to the routine manner in which children respond to and cope with everyday situations were collected, this study did not probe the coping pattern of parents before contact with the hospital. In view of the incidence and intensity of the reports of parental anxiety, further exploration of the significance of the events to the mother, based on an understanding of her past experience with stress, would seem to be an important area to consider. The GHQ specifically probed recent changes in the coping behaviours of the

parent, this approach focused attention specifically on the immediate concerns of the parent in relation to the child's admission. It may also be significant to assess the manner in which the parent coped with previous stresses in her life, in a similar manner to the data on the child's responses to previous stress. This addresses the importance of cognitive appraisal, which is central to stress and coping theory. Hobfall (1989) and Lazarus (1986) make the salient point that personal meaning, or significance of the events to the individual is a function of the past experience, as well as the impact of the present context. Further study would require to address the potential, as well as the limitations of securing data relating to the parents past history in an attempt to understand more fully responses to the stress of the specific context of paediatric hospitalisation.

Involvement of fathers and siblings.

Mention has been made to the nominal presence of father as respondent in this study (2/90). This is considered to reflect current societal norms (Graham, 1984), rather than the willingness and interest of the father to be active participants in the experience. In fact a further 35 fathers were also present during the admission interview but preferred the mother to act as respondent.

The position of the siblings was addressed at the early stages of data collection in relation to the organisation and planning required of the mother prior to the child's admission (qu.5). The importance of mothers presence and her impact as a mediator of the distress experienced by the hospitalised child, is an important finding of this study. The presence of siblings in the paediatric ward, a situation not as yet commonplace in paediatric hospitals, would come some way towards alleviating the anxiety of mothers in relation to sibling well-being, as well as influencing the coping responses of the mother and the level of discontinuity experienced by the hospitalised child (Hall, 1987).

The Temporal aspects of Post-Hospital follow-up

An important limitation of this study is that the period of follow-up of children was confined to two weeks post-transfer. This was necessary in view of the real restrictions of time and funding to complete the study. Reference has been made in the literature to the value of studying the longer-term effects of hospitalisation in relation to the effect of this experience on the child's subsequent responses to future medical and social stressors. This important area would require further study which at the outset would address the additional resources required by such longitudinal research.

12:11 Methodological Comment

The combined method applied to this study is considered to have proved of considerable value in answering the research questions and in providing useful data which, when analysed within an interpretive framework, using the approach of discourse analysis, led to an understanding of the nature and manner of child and parent coping across the course of the experience. Triangulation employed in this as in other studies, had the additional benefit of strengthening the validity of the empirical evidence obtained.

Issues of reliability and validity were addressed at the outset with reference to the piloting of the instruments developed by the researcher and by the use of the other instruments in previous well validated studies (chapter 5). However, further attention requires to be given to the sensitivity of the measures used in eliciting information about child responses during health care. In particular, the development of instruments which would address the wide age range studied are considered in the light of the present findings to be important if the discrete differences are to be seen. The qualitative analysis highlighted the importance of credibility and fit as concepts of value when interpreting qualitative data (Guba and Lincoln, 1981). The success of such efforts lies not only in the level of understanding of child and parent responses subsequently achieved, but also in the ability of the reader to arrive at a similar understanding.

i) The Issue of Significance

Reference has been made throughout this discussion to the relative contribution of analysis of the quantitative and qualitative data in addressing the research questions. In particular, the perspectives offered by both approaches have been identified and considered in relation to the merits of quantitative and qualitative data (chapter 9-11). As discussed in chapter 9, the quantitative analysis served as a frame of reference between the two approaches to analyses adopted in this study. The question of significance, that is whether the observed change was due to a chance variation or to the intervention efforts of the investigator was considered in chapter 9.

The quantitative data were seen to signal attention to aspects of the findings which required to be explored further within the interpretive framework of the qualitative analysis. The rationale for the compilation of summary variables was addressed (9:3). As a pre-requisite to the process of aggregating scores, an examination of the presence of significance in individual items which made up each summary was undertaken. This was important, since by the very process of aggregating items, important data were subsumed within the summary score. While this process did demonstrate the presence of significance in some items, this information was considered to be more appropriately addressed in

relation to the qualitative analysis, where an understanding of the factors which contributed to the presence of significance in some items and non-significance in others was addressed.

The presence of non-significant findings on the eight summary variables was considered in relation to three important methodological points. The first being the overall sample size ($n=90$). This was further divided into three sub-groups, assigned by way of random sampling. In essence three groups of 30 imposed considerable restrictions on the approach to analysis. The second point considered was that of the power of the statistical tests applied to the data. As discussed in chapter 9, non-parametric tests appropriate to nominal data were selected. The power of the Kruskal-Wallis statistic was also influenced in turn by the three group analysis. A final point which was considered to contribute to the absence of statistical significance within the summary variables was that of sensitivity of the instruments. The possibility of developing further, instruments which are more sensitive to subtle changes in the child's coping behaviour during hospitalisation requires to be addressed. It was suggested that this may be achieved by limiting the number of variables studied and restricting the number of category responses available on each instrument (9:7).

Interpretation of the qualitative analysis informed an understanding of the individual items which were found to show a level of significance. In particular, attention to the in-hospital adjustment of the child showed a correlation between preparation and manifest upset and co-operation ($p=0.0015$) during maximum stress points. The advantages of triangulation were seen as the findings from the quantitative analysis presented a condensed conceptual view which was then developed and interpreted within the discourse analysis framework of the qualitative analyses. In summary, the importance of systematic study of a new approach to the preparation of children and their parents for paediatric hospitalisation was important to avoid erroneous acclaim which may have arisen from mono-method study. The balance between securing data that was known to be objective, and attempts to capture the meaning of the experience for the respondents was achieved by the approach adopted in the study.

ii) Measuring the Effects of the Experimental Intervention.

This study assessed the secondary effects of preparation, that is changes in the child's behavioural and subjective responses. It would seem a useful extension of this study to consider evaluating the impact of the experimental treatment on the child conceptions of illness and medical treatments. This approach would clearly require the child as the

direct data source rather than relying exclusively on parental perceptions. In addition, Peterson (1989), makes the point that evaluation of the effect of the 'knowledge component' of preparation programmes would be an appropriate way to assess change. Within stress and coping theory, steps to assess the child's knowledge and understanding of the forthcoming events after a preparation programme would address the importance of re-appraisal. Again this would involve the researcher in securing data directly from the child, since it is accepted to be unreasonable to place any further requests upon the nursing staff.

The 'Additional Attention' Group - Control group ii Diary.

It has been emphasised throughout this study that the additional attention given to the second control group was unrelated to preparation and took the form of asking the mother to complete on a daily basis, a record of any changes noted in her child after he knew about the forthcoming admission, that is 7 days prior to hospitalisation. The overall intent of this approach was to attempt to distinguish between the effects of the experimental intervention and the effects of additional attention. The diary seemed to fulfil this aim. However, the parents made reference to the intrinsic value of being able to focus on a tangible aspect of the child's responses. The diary was developed by this researcher and was personalised for each child. Most of the (24/30) parents expressed positive opinions about being asked to share the child's experience, many mothers also commented that it created an atmosphere of genuine interest in and concern for the child as an individual. The writer would now put forward the suggestion that, given the positive effect of this simple mode of contact with the child and parent before admission, consideration of this diary as a regular part of pre-admission care which could then be used by the nursing staff as they compile a nursing care plan on admission, seems worthy of consideration.

12:12 CONCLUSION.

...And the end of all our exploring
Will be to arrive where we started
and to know the place for the first time.

(TS Eliot,1949)

This study has yielded a very rich harvest of data, some of which have been presented in this study. I set out with a set of tentative research questions, and 'at the end of my exploring' the research questions were answered. In addition, a range of other interesting unasked questions worthy of further investigation were raised. Part of the discipline of research is that of being, or learning to become, circumspect in relation to the legitimate arena of ones' own study. The conceptual framework of the stress and coping paradigm proved to be an invaluable tool in focusing on the study of stress and coping within the medical setting. The process was epitomised as parents and their children were seen to travel together throughout the stages of reaction and varying degrees of acceptance of the medical procedures and their sequelae. The development of a model from this study, based on the stress and coping paradigm which articulates more closely, the experience of the child and his parent during the experiences which constitute the process of hospitalisation and surgery, is viewed as an exciting development which may contribute to the conceptual framework of nursing practice. The model may be applied to planning the pre-admission care of the child and family and span his in-hospital and post-hospital experience.

In answering the research questions, the discrete elements of the experience were apparent as the efficacy of the experimental treatment was examined and the condition of the control groups studied. The implications of this study relates not only to the main issue under investigation, that is, does preparation for paediatric hospitalisation mitigate the distress, but also raises broader philosophical issues in relation to health care provision, quality assurance and the legitimate role of the nurse in representing the best interests of the hospitalised family.

The value of a fresh appraisal tested as a more discriminating approach to the preparation of the child and parents for paediatric hospitalisation, is put forward by this analysis. The approach to preparation tested in this study may be seen as the vehicle for the further development and progress of preparation initiatives. The many proposals made in this study can be thought of as a potential contribution towards family centred

care. It is clear that the traditional form of hospital organisation is inimical to the welfare of young patients from the earliest point of contact with the organisation. There are also examples where aspects of the hospital care during in-patient treatment is seen to provide an atmosphere which is at odds with its therapeutic purpose, that is, of delivering an excellence in clinical care and treatments. This clinical care clearly involves attention to the psycho-social needs of the child as well as to those of the parent. When parents were excluded from involvement in their child's care, particularly during times of perceived 'maximum stress', the anxiety experienced by both child and parent was found to be accentuated. It is important that nursing actions reflect not only the ultimate goal of practice-that is; delivering an excellence in clinical care, but also, should reflect the values and priorities of the child and parent.

It is not simply a case of identifying the most vulnerable children and taking steps to protect them from the distress of hospital. The issue is that of addressing the problems encountered by all children who have to undergo medical treatments. Good practice is a union of 'being' and 'doing'. This union, rather than reflecting an individual achievement, represents the co-operative accomplishment by those who constitute and contribute to practice. The present investigation proved to be a co-operative venture between the child and his parents; the ward staff and the researcher. The study was developed from practice and conducted within the climate of current changes in practice and education. Practice can never be static, but dynamic in ways that continually realise the potential for improvement and which will move practice forward toward what it ought to become.

The role assigned to the family is becoming an increasingly important one. For example, 'Care by Parents schemes' are in their infancy, but the potential for a dynamic and participating role for parents which would integrate the family into the hospital community during the period of medical treatments, rather than maintain the present institutional boundaries which are still, in spite of the more facilitative atmosphere, set in relation to specific areas of the child's in-hospital experience. As Carol Gilligan (1982) wrote,

We need to move away from the paralysing injunction not to harm, into learning through sympathy and shared humanity... Viewing the world comprised of relationships, rather than people standing alone, a world that coheres through human connection rather than through a system of rules...(p.32).

The overall experience of the child and parent was perceived to be positive. With the important exceptions of preparation for the experience; and the imposed exclusion of the parents from the ward at a time when most parents felt they should be with their child; parents expressed satisfaction with the quality of care they received. Responding to the

negative as well as sharing the positive outcomes of this study is considered to be an important commitment which the researcher will undertake. The emotional adjustment of the children prepared within the experimental intervention was found to be adaptive and developmentally useful. The parents within the treatment group were found to cope more adaptively with the experience and appeared to manage their anxiety throughout the process. The potential to adopt the approach to preparation which was tested in this investigation and which can be implemented without additional resources, is an important development of paediatric care.

To establish that a research intervention has a positive effect is one thing, but to achieve a transformation and re-direction in aspects of paediatric practice is quite another. The challenge for nursing practice in the 1990's is to address the realities of economic and social pressures and to establish clear goals for intervention. It is even more important, in the light of such changes, to avoid practice being so narrowly defined as to exclude the less easily assessed aspects of social and emotional care.

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umsheugh Gardens Edinburgh EH3 7QQ Telephone 031-225 1341

Your Ref
Our Ref DJMacD/CAL
Date 13 March 1990
Enquiries to Mr D J MacDonald
Ext. No. 2326

Ms Rebecca G Strachan
Nursing Research Unit
Department of Nursing Studies
12 Buccleuch Place
Edinburgh
EH8 9LJ

Dear Ms Strachan

NURSING RESEARCH STUDY

Thank you for your letters of 16th and 26th February 1990 about your proposed research project. I am pleased to approve this in principle and will write to Miss Atkinson, Director of Nursing Services at the Royal Hospital for Sick Children and Mr Purves, Director of Nursing Services of the City Hospital to tell them briefly about your research and saying that you will be in touch with them shortly, to make arrangements to discuss the project more fully. I would advise you to wait until the beginning of the week commencing 19th March 1990, before getting in touch with them to allow the mail to arrive.

Yours sincerely

D J MacDonald
Director of Manpower and Nursing Services

PS I would also suggest you make contact with Mrs S Welton, Secretary to Paediatrics/Reproductive Medicine Ethics of Medical Research Sub-Committee, Administration Department, Simpson Memorial Maternity Pavilion, Lauriston Road, Edinburgh to advise her of your research project.

>



181 Morrison Place Edinburgh EH3 9EF Telephone 031-229 2477 Ext.

SIMPSON MEMORIAL MATERNITY PAVILION

Your Ref
Our Ref SW/JHNL
Date 29.1.90
Enquiries to
Ext. No.

Ms. Rebecca G. Strachan,
Nursing Research Unit,
University of Edinburgh,
12 Buccleuch Place,
Edinburgh, EH8 9LJ.

Dear Ms. Strachan,

Paediatric/Reproductive Medicine Ethics of Medical Research Sub-Committee
Protocol 38/87: The Emotional Adjustment of Children and their Parents to Paediatric Hospitalisation - Extension

The documents submitted you in respect of the above were considered by the Sub-Committee at their last meeting, and I have pleasure in informing you that ethical approval has been granted to this extension.

Please note that if new ethical issues arise, you should consult with myself or the Chairman to ascertain if a reapplication requires to be made.

Yours sincerely,

MRS. SHONA WELTON,
Secretary,
Paediatric/Reproductive Medicine
Ethics of Medical Research Sub-Committee.



enbank Drive Edinburgh EH10 5SB Telephone 031-447 1001

DEPARTMENT OF ANAESTHETICS

r Ref
Ref JCM/JH
30th March 1990

Consultants:
Administrative Consultant Dr J.C. McIntyre
Dr W.A. Chambers
Dr G.M.R. Bowler
Dr G.C. Pugh
Dr E.L. Lloyd
Dr W.R. MacRae
Dr L.V. Martin
Dr Hui Pin Teh

Miss Rebecca G. Strachan,
Nursing Research Training Fellow,
Nursing Research Unit,
University of Edinburgh,
12 Buccleuch Place,
Edinburgh,
EH8 9LF.

Dear Miss Strachan,

Children in Hospital

Thank you for your letter of 27th March 1990 with a copy of the scoring form which you intend to use.

I think I can speak for my colleagues also when I say that we will be happy to complete the part relevant to induction of anaesthesia.

I presume filling of the form will start in the ward, follow the child to theatre, and back to the ward for completion.

Yours sincerely,

J.C. McIntyre
CAR Anaesthetics

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

RESEARCH PROPOSAL

University of Edinburgh
Nursing Research Unit
Royal Hospital for Sick Children
EDINBURGH

I understand that Rebecca G Strachan is a Sick Childrens Nurse studying the value of two different approaches to the preparation and support given to parents and their children in preparation for admission to the Ear Nose and Throat Department of the Royal Hospital for Sick Children.

The study requires Mrs Strachan to ask parents to co-operate by completing, with the researcher, a questionnaire on two occasions. The first during your child's admission, and the second, two weeks after your child has returned home. This second questionnaire will be posted out to you and will include a S.A.E. for your reply. All information gained from the questionnaires will be absolutely confidential. Neither you nor your child will be identified as an individual in any subsequent report of this study. I understand that there may be no direct benefits to me or my child on this occasion, but the study may provide useful information to nurses in future. I have had the opportunity to think about my participation in this study and to talk to the researcher about it. I may contact her at any time during the study: [667-1011 extension 6275].

Also, I understand that I am free to withdraw from the study at any time.

Name: Signature of subject Parent/Guardian:

.....

Name of

Witness: Signature of Witness:

.....

Royal Hospital for Sick Children,
Sciennes Road,
Edinburgh.
Telephone; 667: 1991

Dear Parent,

In preparation for your child's admission to **WARD 6** within the next few days, we would like to invite you to bring to the ward on **THURSDAY**,..... after school between **4.0pm - 4.15pm**.

The purpose of this visit is to offer parents the opportunity to discuss with the nursing staff, any queries, or to provide further information about their child's forthcoming admission to hospital for planned surgery. Also, we hope the occasion will present the child with the opportunity to see around the ward and to meet with some of the other children who will be in ward 6 at the same time. The Nursing Staff would also be very glad of the chance to meet you and your child and to talk about the experience of admission to hospital. It is hoped that we will be able to show a film about admission to hospital for Ear, Nose and Throat surgery. This of course, would be entirely optional.

There is currently a Nursing Research Study taking place within the ward, the purpose of which is to look at the preparation of children and their parents for admission to hospital for planned surgery. We would be most grateful if you wish to consent to take part. However, should you prefer not to, we would of course be happy to respect your wishes. This in no way influences the care your child will receive in hospital.

We hope that you will be able to bring your child along to ward 6 on the above date and look forward to meeting with you then.

With Best Wishes,

Yours sincerely,

Ward Sister.

NURSING RESEARCH STUDY.

Nursing Research Unit,
University of Edinburgh
12, Buccleuch Place,
Edinburgh, EH8 9LF.

Dear Parent,

Thank you for kindly agreeing to take part in this Nursing Research Study, the nature of which is explained on the first part of the questionnaire which I now ask you to complete.

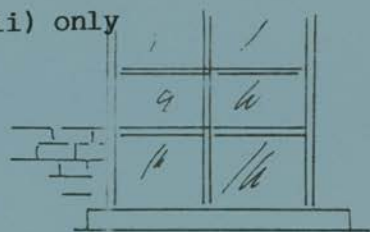
Would you please fill this in **before** your child is admitted to hospital, and bring the completed forms, together with your consent, when you come into hospital **on the day** of your child's admission.

Thank you for your help with this, I look forward to meeting you and your child when you arrive in the ward.

Yours sincerely,

Rebecca G. Strachan,
Nursing Research Training Fellow.

Control Group (ii) only



· HOSPITAL ·

CHILD'S
Pre - Admission
DIARY

Child's Name

Sex:

Completed by Mother []
" " Father []

Child Study No:
Date of Birth:
Parents No:
Group Assign.
Instrument No:

PRE-ADMISSION DIARY

Please keep this daily diary starting seven days before your child is admitted to hospital.

The things of particular interest are noted at the top of each day's diary. Please also record any other part of your child's day-to-day behaviour or activities which you think are different in any way.

Also, I would be glad if you could comment on your own patterns of activity or behaviour which you think may be connected to your child's forthcoming admission.



..... Diary

Day **1** (i.e. one week before expected admission)

1. Has your relationship with your child changed in any way since he/she learned about admission to hospital. For example is your child more 'clingy'; Less willing to go to school or nursery; Less willing to be left with child minders while parents are out; Does he/she seem angry with parents at all.

.....
.....
.....

2. Has his/her relationship with the family changed.

.....
.....
.....

3. Are his/her sleeping habits the same or does he wake in the night; go into parents room.

.....
.....
.....

4. Is he happy at school/nursery

.....
.....

5. Can he/she concentrate on homework/games etc.

.....
.....

6. Are there any changes you notice in his/her habits.

.....
.....
.....

Now you have commented on your child's behaviour how do you feel.

.....
.....
.....

..... Diary

Day **2** (i.e. one week before expected admission)

1. Has your relationship with your child changed in any way since he/she learned about admission to hospital. For example is your child more 'clingy'; Less willing to go to school or nursery; Less willing to be left with child minders while parents are out; Does he/she seem angry with parents at all.

.....
.....
.....

2. Has his/her relationship with the family changed.

.....
.....
.....

3. Are his/her sleeping habits the same or does he wake in the night; go into parents room.

.....
.....
.....

4. Is he happy at school/nursery

.....
.....

5. Can he/she concentrate on homework/games etc.

.....
.....

6. Are there any changes you notice in his/her habits.

.....
.....
.....

Now you have commented on your child's behaviour how do you feel.

.....
.....
.....

..... Diary

Day **3** (i.e. one week before expected admission)

1. Has your relationship with your child changed in any way since he/she learned about admission to hospital. For example is your child more 'clingy'; Less willing to go to school or nursery; Less willing to be left with child minders while parents are out; Does he/she seem angry with parents at all.

.....
.....
.....

2. Has his/her relationship with the family changed.

.....
.....
.....

3. Are his/her sleeping habits the same or does he wake in the night; go into parents room.

.....
.....
.....

4. Is he happy at school/nursery

.....
.....

5. Can he/she concentrate on homework/games etc.

.....
.....

6. Are there any changes you notice in his/her habits.

.....
.....
.....

Now you have commented on your child's behaviour how do you feel.

.....
.....
.....

..... Diary

Day **4** (i.e. one week before expected admission)

1. Has your relationship with your child changed in any way since he/she learned about admission to hospital. For example is your child more 'clingy'; Less willing to go to school or nursery; Less willing to be left with child minders while parents are out; Does he/she seem angry with parents at all.

.....
.....
.....

2. Has his/her relationship with the family changed.

.....
.....
.....

3. Are his/her sleeping habits the same or does he wake in the night; go into parents room.

.....
.....
.....

4. Is he happy at school/nursery

.....
.....

5. Can he/she concentrate on homework/games etc.

.....
.....

6. Are there any changes you notice in his/her habits.

.....
.....
.....

Now you have commented on your child's behaviour how do you feel.

.....
.....
.....

Day **5** (i.e. one week before expected admission)

1. Has your relationship with your child changed in any way since he/she learned about admission to hospital. For example is your child more 'clingy'; Less willing to go to school or nursery; Less willing to be left with child minders while parents are out; Does he/she seem angry with parents at all.

.....
.....
.....

2. Has his/her relationship with the family changed.

.....
.....
.....

3. Are his/her sleeping habits the same or does he wake in the night; go into parents room.

.....
.....
.....

4. Is he happy at school/nursery

.....
.....

5. Can he/she concentrate on homework/games etc.

.....
.....

6. Are there any changes you notice in his/her habits.

.....
.....
.....

Now you have commented on your child's behaviour how do you feel.

.....
.....
.....

..... Diary

Day **6** (i.e. one week before expected admission)

1. Has your relationship with your child changed in any way since he/she learned about admission to hospital. For example is your child more 'clingy'; Less willing to go to school or nursery; Less willing to be left with child minders while parents are out; Does he/she seem angry with parents at all.

.....
.....
.....

2. Has his/her relationship with the family changed.

.....
.....
.....

3. Are his/her sleeping habits the same or does he wake in the night; go into parents room.

.....
.....
.....

4. Is he happy at school/nursery

.....
.....

5. Can he/she concentrate on homework/games etc.

.....
.....

6. Are there any changes you notice in his/her habits.

.....
.....
.....

Now you have commented on your child's behaviour how do you feel.

.....
.....
.....

..... Diary

Day **7** (i.e. one week before expected admission)

1. Has your relationship with your child changed in any way since he/she learned about admission to hospital. For example is your child more 'clingy'; Less willing to go to school or nursery; Less willing to be left with child minders while parents are out; Does he/she seem angry with parents at all.

.....
.....
.....

2. Has his/her relationship with the family changed.

.....
.....
.....

3. Are his/her sleeping habits the same or does he wake in the night; go into parents room.

.....
.....
.....

4. Is he happy at school/nursery

.....
.....

5. Can he/she concentrate on homework/games etc.

.....
.....

6. Are there any changes you notice in his/her habits.

.....
.....
.....

Now you have commented on your child's behaviour how do you feel.

.....
.....
.....

CONTACT NO: FOR RESEARCHER

667 - 1011 (Extension 6275)
Mrs Rebecca Strachan
Nursing Research Unit
University of Edinburgh

Instrument No: 2

PRE-ADMISSION QUESTIONNAIRE

As requested in an earlier letter would you now please answer the following questions which appear in two parts:-

Part (1) Please answer this section before your child knows he/she is being admitted to hospital.

Part (2) Please complete this section after your child finds out about hospital admission.

It is appreciated that not all the questions may seem to be appropriate for your child, this is because the study includes children within the wide age range 3 - 7 years the questions being the same for everyone. Could you please, however, answer all questions by ticking [] the response most suited to your child.

Office Use only

Code

Child Study No: [] 1-2
Sex: [] 3
Instrument No: [] 4
Group Assign. [] 5
Date of Birth: [] 6-11
Parents No: [] 12-13

Completed by Mother []
" " Father [] 14

PART I

Before your child knows about hospital

Does your child need a comforter
e.g. old blanket, favourite teddy. 2 1
Yes No
[] [] 15

If yes:

Does he/she: Use it only at bedtime 1 []
Use it only when tired or upset 2 [] 16
Use it often during the day and at night 3 []

Does your child suck his/her thumb or fingers Yes No
2 1
[] [] 17

If yes: Only at bedtime 1 []
Only when tired or upset 2 [] 18
Often during the day and/at night 3 []

Does/

17. How would you describe your child's appetite:

Eats well, no problems at all	1 []	
Has some food fads	2 []	34
Very difficult, poor appetite	3 []	
Other - please describe	[]	

.....	
.....	35
.....	

PART II

Please complete after your child knows about hospital

18. When did your child find out he/she was coming into hospital

- Two weeks before []
- 1 week before [] 36
- A few days []
- Other []
- please specify

.....
.....
.....

19. Did your child ask many questions about hospital

	1	2
	Yes	No
	[]	[] 37

20. If yes: Please list the things your child wanted to know.

.....
.....
..... 38
.....

21. Did your child appear anxious about hospital

	2	1
	Yes	No
	[]	[] 39

22. If Yes: How did this anxiety show

.....
..... 40
.....

23. Did you talk to your child about hospital

	1	2
	Yes	No
	[]	[] 41

24. If Yes: When I thought the time was right

	2	[]
Chatted regularly about the event	1	[] 42
Only when child brought subject up	3	[]

25. If you discussed hospital with your child - please describe briefly the things you talked about

.....
..... 43
.....

26. Did you notice any change in your child's behaviour immediately after he/she knew about admission

	2	1
	Yes	No
	[]	[] 44

If/

If Yes: Could you please describe these changes
.....
.....
.....

27. Did you have to do anything special to help your child handle the situation of coming into hospital
Yes No
[] [] 46

If Yes: What did you do.
.....
.....
..... 47

28. Has this planned admission to hospital brought about any change in the family routine
Yes No
[] [] 48

If Yes what changes have you noticed
.....
.....
..... 49

If more than one child in the family:-

29. Has this planned admission affected the other children in the family
Yes No
[] [] 50

If Yes: In what way are they affected please describe
.....
.....
..... 51

30. Do you expect your child's behaviour to be different during his/her time in hospital
Yes No
[] [] 52

If Yes: In what way do you expect it to change
.....
.....
..... 53

31. When your child is in the Ward, do you expect to take part in his/her care.
Yes No
[] [] 54

If Yes: Please describe what you might expect to be doing
.....
.....
..... 55

Can/

32. Can you please describe what you expect of the hospital experience in relation to:-

i) Co-operation between nurse and parent in caring for your child.

.....
.....
.....
.....

ii) Information and support from the staff.

.....
.....
.....
.....

Thank you for filling this in. Please bring it with you when your child is admitted.

Instrument No: 3

ADMISSION SCHEDULE

Office Use Only

Code

Child Study No:
Sex:
Instrument No:
Group Assig.
Date of Birth:
Parents No:

1-2
 3
 4
 5
 6-11
 12-13

Completed by Mother
" " Father 14

Qu.1. How many children are in the family 15

2. What place does this child have in the family e.g.
1st
2nd
3rd 16
4th

3. Have you had to make any practical arrangements as a result of your child's admission
Yes No 17

4. If Yes: Do you feel happy with these arrangements
1 Yes 2 No 18

5. If you do not feel happy, what difficulties do you think you have

Please comment:-

.....
..... 19
.....
.....

6. Does your child attend playgroup, nursery, primary school
 20-22

7. Does/

		1	2	
		Yes	No	
7.	Does he/she enjoy going to school, nursery/ no problems	[]	[]	23

If no:-

Does he/she	appear a little anxious about school	1	[]	
	shows occasional clinging behaviour	2	[]	24
	is tearful and distressed	3	[]	

If applicable:

8.	Does your child play well with brothers/sisters	1	[]	
	occasional conflicts, usual rivalries	2	[]	25
	does not get along at all well	3	[]	

9.	Does your child enjoy friends at school	1	[]	
	Does he/she play well as part of a group	1	[]	26
	Prefers one special friend	2	[]	
	Appears to play by himself	3	[]	

0.	Does your child talk to you about his/her day at school	1	[]	
	Chats about it freely	1	[]	27
	Only when encouraged to	2	[]	
	Prefers not to talk about his day	3	[]	

1.	How long before admission did he/she know about coming into hospital			
	Two weeks or more		[]	
	One week		[]	28
	A few days		[]	
	Other -			
	Please specify			
			
			
			29
			

2.	How did your child react to the news of hospital as soon as he/she was told			
	Curious to find out more	1	[]	
	Did not seem anxious	1	[]	
	A Little anxious, needed reassurance	2	[]	30-31
	Very upset and anxious	3	[]	

3. How/

13. How do you think your child accepted the news of hospital admission

- Did not seem to affect him adversely 1 []
- Wanted to talk about it 1 []
- Seemed anxious and uncertain 2 [] 32-33
- Very distressed and upset by it 3 []

14. How does your child react to visits to the Doctor

- Is quite matter of fact - goes without fuss 1 []
- Is reluctant to go, needs persuasion 2 []
- Is very difficult, tearful and anxious 3 [] 34

15. Has your child had dental treatment before e.g. Fissure sealing, fillings.

Yes No
[] [] 35

16. How did your child behave during visits to dentist

- Was calm and co-operative 1 []
- A bit anxious but co-operative 2 [] 36
- Distressed and unwilling to co-operate 3 []

17. Has your child had any distressing experiences within the last year

Yes No
[] [] 37

If Yes

Could you please describe how he/she dealt with this:-

.....

 38

Please/

Please place a tick [✓] on the column which most closely answers the question 38

	<u>Always</u>	<u>Most of time</u>	<u>Occasionally</u>	<u>Never</u>	
8. Does your child seem upset when Doctors or hospitals are mentioned	4 []	3 []	2 []	1 []	39
9. Is your child willing to go to bed at night	1 []	2 []	3 []	4 []	40
0. Is your child afraid of the dark	4 []	3 []	2 []	1 []	41
1. Does he/she sleep with the night light on	4 []	3 []	2 []	1 []	42
2. Does your child leave his/her bedroom door open	4 []	3 []	2 []	1 []	43
3. Does he/she settle and sleep well	1 []	2 []	3 []	4 []	44
4. Is your child 'dry' at night	1 []	2 []	3 []	4 []	45
5. Does your child have a good appetite	1 []	2 []	3 []	4 []	46
If no to above:-					
5. Does your child have food fads	4 []	3 []	2 []	1 []	47
7. Does he she like a lot of attention at meal times	4 []	3 []	2 []	1 []	48
3. Do you or others persuade your child to eat	4 []	3 []	2 []	1 []	49
6. Does your child find it easy to make up his/her mind	1 []	2 []	3 []	4 []	50
9. Does he/she need a lot of help doing things	4 []	3 []	2 []	1 []	51
8. Does your child spend time trying to win your attention	4 []	3 []	2 []	1 []	52
1. Does your child follow you around the house	4 []	3 []	2 []	1 []	53

Does/

	<u>Always</u>	<u>Most of time</u>	<u>Occasionally</u>	<u>Never</u>	
33. Does your child tend to obey you	1 []	2 []	3 []	4 []	54
34. Is it easy to get him/her interested in doing things	1 []	2 []	3 []	4 []	55
35. Is it easy to get your child to talk to you	1 []	2 []	3 []	4 []	56
36. Does your child tend to lose his/her temper	4 []	3 []	2 []	1 []	57
37. Does he/she find activities to keep him/her occupied	1 []	2 []	3 []	4 []	58
38. Does your child have bad dreams - and wake in the night	4 []	3 []	2 []	1 []	59
39. Does your child get upset when you leave him/her with another adult	4 []	3 []	2 []	1 []	60
40. Does he/she seem to avoid or be afraid of new things	4 []	3 []	2 []	1 []	61
41. Does your child take special care of toys, books & games	1 []	2 []	3 []	4 []	62
42. Does he/she seem afraid or shy around strangers	4 []	3 []	2 []	1 []	63
43. Does your child seem afraid to leave the house with you	4 []	3 []	2 []	1 []	64
44. Does mother have a paid employment		Yes []	No []		65
45. What is the occupation of the principal earner					66

Instrument No: 4

	<u>Office Use only</u>	<u>Code</u>
Child Study No:	[]	1-2
Sex:	[]	3
Instrument No:	[]	1-14
Group Assig.	[]	5
Date of Birth:	[]	6-11
Parents No:	[]	12-13

Completed by Mother []
 " " Father [] 14

PARENTS RESPONSE

We should like to know how your health has been in general over the last two weeks. Please answer all the following questions by underlining the answer which you think most closely applies to you. Only recent and present complaints should be noted - not those in the past.

Have you recently:

- | | | | | | | |
|----|---|---------------------------------|---------------------------------|-------------------------------------|-----------------------------------|----|
| 1. | Been able to concentrate on what you are doing | Better ⁰ than usual | Same ⁰ as usual | Less ¹ than usual | Much ² less than usual | 15 |
| 2. | Been sleeping well | Better ⁰ than usual | Same ⁰ as usual | Less ¹ than usual | Much ² less than usual | 16 |
| 3. | Been satisfied with the way you carried out your tasks. | Better ⁰ than usual | Same ⁰ as usual | Less ¹ than usual | Much ² less than usual | 17 |
| 4. | Been feeling it easy to get on with people. | Better ⁰ than usual | Same ⁰ as usual | Less ¹ than usual | Much ² less than usual | 18 |
| 5. | Felt capable of making decisions | More so than usual ⁰ | Same as usual ⁰ | Less than usual ¹ | Much less than usual ² | 19 |
| 6. | Been feeling under strain | Not at all ⁰ | No more than usual ⁰ | Rather more than usual ¹ | Much more than usual ² | 20 |
| 7. | Have/ | | | | | |

Have you recently:

7.	Been able to enjoy your normal day/day activities	More ⁰ so than usual	Same ⁰ as usual	Less ¹ than usual	Much ² less than usual	21
8.	Been feeling panicky for no good reason	Not at ⁰ all	No more ⁰ than usual	Rather ¹ more than usual	Much ² more than usual	22
9.	Found things getting on top of you	Not at ⁰ all	No more ⁰ than usual	Rather ¹ more than usual	Much ² more than usual	23
10.	Been feeling unhappy and depressed	Not at ⁰ all	No more ⁰ than usual	Rather ¹ more than usual	Much ² more than usual	24
11.	Been losing confidence in yourself	Not at ⁰ all	No more ⁰ than usual	Rather ¹ more than usual	Much ² more than usual	25
12.	Been feeling reasonably happy	More ⁰ so than usual	About the ⁰ same as usual	Less ¹ so than usual	Much ² less than usual	26
13.	How do you now feel about your child's admission to hospital for this planned small operation.					
					
					27
14.	Are there any other comments you wish to make about your own feelings or health now.					
					
					28

Reference:-

General Health Questionnaire
 by permission General Practice Research Unit
 NFER Publishing
 (abbreviated G.H.Q.)

5. Do you expect to take part in your child's care during the time in hospital

1	2	
Yes	No	
[]	[]	29

5. If yes, and there are other children at home - did you have any difficulty arranging their care

2	1	
[]	[]	30

7. Can you recall how you felt when Doctor first suggested admission to hospital for your child

.....

..... 31

3. How do you feel now about your child's admission and surgery

.....

..... 32

4. How do you expect your child to cope with the experience of hospital admission

.....

..... 33

6. Do you expect your child's behaviour to be different in any way when he/she returns home

1	2	
Yes	No	
[]	[]	34

6. If Yes: Please describe the changes you might expect

.....

..... 35

8. Have you felt any differently in the last few days

	Yes	No	
In relation to - sleeping	1 []	[]	
eating patterns	2 []	[]	36
general coping and tolerance	3 []	[]	

8. If yes to any of the above - please comment on how you feel

.....

..... 37

8. How/

24. How do you expect to cope with your child's admission and surgery

.....
.....
.....
.....
.....

Instrument No: 5

Child's Name

Code

Child Study No: [] 1-2
Sex: [] 3
Instrument No: [] 1-13
Group Assign. [] 5
Date of Birth: [] 6-11
Parents No: [] 12-13

MANIFEST UPSET SCALE

TOTAL SCORE

PARENTAL PRESENCE

Constant []
Intermittent []
Absent []

SCALE

1. Indicating little or no fear or anxiety, calm appearance, no crying or verbal upset.
2. Some crying and verbal protest. Can be comforted by nurse or by mother. Settles fairly quickly.
3. Crying, rather more difficult to comfort. Required continued support from mother or nurse.
4. Very distressed, protesting loudly, difficult to comfort. Child unable to accept re-assurance.
5. Extreme emotional distress, agitated, crying or screaming. Required constant nursing presence. Very difficult to comfort.

Non category response - please describe fully.

OBSERVER COMMENTS

Observational Data/

Instrument No: 5

CO-OPERATION SCALE

Code

Child Study No:	[]	1-2
Sex:	[]	3
Instrument No:	[]	1-13
Group Assign.	[]	5
Date of Birth:	[]	6-11
Parents No:	[]	12-13

SCORE

PARENTAL PRESENCE

Constant	[]
Intermittent	[]
Absent	[]

SCALE

1. Complete co-operation; may include active participation in and assistance with the procedure.
2. Mild or initial resistance, or passive participation without assistance.
3. Initial resistance, some crying but could be comforted and helped to co-operate.
4. Upset and crying. Resistent to nursing or medical treatments. Required considerable support and comfort.
5. Extreme resistance. Strong avoidance. Child unable to respond to explanations or persuasion.

Non Category Response - please describe fully

Observer Comments

Co-operation with the following:-

Co-operation with the following:-

SCORE 1-5

- | | |
|--|-------|
| 1. Examination by Doctor, on admission | |
| 2. Pre-operative medication (oral Administration) | |
| 3. Resistance to induction of anaesthesia: recorded
by the anaesthetist | |
| 4. Post-operative settling with sedation [] | |
| without sedation [] | |
| 5. Co-operation with and ease of post-operative fluid
intake | |
| 6. Acceptance of and ease of eating, first meal
post operatively | |
| 7. First post-operative voiding. | |

Ref: Wolfer & Visintainer (1979)

Instrument No: 6

Post Hospital Questionnaire

(Ref: Vernon-Foley 1966
(Azarnoff; Bourque 1975

Office Use

Child Study No: 1-2
Sex: 3
Instrument No: 1-14
Group Assig. 5
Date of Birth: 6-11
Parents No: 12-13

Completed by Mother
" " Father 14

1. Has your child returned to school, nursery or playgroup Yes No
 15

If Yes: How did he/she behave
Took it in his/her stride - no problems
A bit clingy, but settled down
Seemed anxious about going back 16
Tearful and distressed

2. How do you think your child coped with the overall hospital experience Yes No

Coped well, no ill effects
Needs comfort and reassurance, upset by event 17
Very upset by the experience

Other 18
Please specify
.....
.....

3. Do you notice any things for the better in your child's Yes No

General health
Hearing 19
Speech

4. Do you notice any other changes for the better in your child since he/she returned home Yes No
 20

If Yes: Please describe what these changes are:-
..... 21
.....
.....

5. Has/

5. Has your child needed any medicines since he/she returned home Yes No
[] [] 22

If Yes: what were they for?
..... 23

6. How do you think your child has recovered physically [] []
 Completely back to normal [] []
 Still a bit upset 'peaky' - tired [] [] 24
 Complaining of aches & pains - generally not right [] []
 Treated by Doctor for problems [] []

7. Are there any aspects of your child's care you feel you need advice about Yes No
[] [] 25

If Yes: What are they
..... 26
.....
.....

Thank you for completing this section.

Please now complete the following questions which specifically asks you to compare your recollection of your child's behaviour before admission, with that since he/she returned home. Please place a tick [✓] under the column that most closely matches your child's behaviour now.

		Much less than before	Same as before	Less than before	More than before	Much more than before
		[⁰]	[¹]	[⁰]	[²]	[³] 27
8. Does your child seem upset when Doctors/hospitals are mentioned.		[]	[]	[]	[]	[]
9. At bedtime, does your child -	Yes No					
Go to bed without a fuss	0 [] []	[]	[]	[]	[]	[]
Has to be persuaded	1 [] []	[]	[]	[]	[]	[] 28
Is difficult to settle	2 [] []	[]	[]	[]	[]	[]
10. Does he/she sleep with a night light on		[]	[]	[]	[]	[] 29
11. Does your child wake during the night		[]	[]	[]	[]	[] 30
If <u>more than before</u> -						
Does he/she have bad dreams		[]	[]	[]	[]	[]
12. Does he/she come into parents bed		[]	[]	[]	[]	[] 31
13. Does your child stay dry in the night		[]	[]	[]	[]	[] 32
14. Does/						

	Much less than before	Same as before	Less than before	More than before	Much more than before	
14. Does he/she find it easy to make up his/her mind	3 []	1 []	2 []	0 []	0 []	33
15. Does your child need a lot of help doing things	0 []	1 []	0 []	2 []	3 []	34
16. Does your child try to win your attention	0 []	1 []	0 []	2 []	3 []	35
17. Does he/she follow you around the house	0 []	1 []	0 []	2 []	3 []	36
18. Does your child tend to obey you	3 []	1 []	2 []	0 []	0 []	37
19. Is it easy to get him/her interested in doing things	3 []	1 []	2 []	0 []	0 []	38
20. Is it easy to get your child to talk to you	3 []	1 []	2 []	0 []	0 []	39
21. Does your child tend to lose his/her temper	0 []	1 []	0 []	2 []	3 []	40
22. Does he/she find activities to keep him/her occupied	3 []	1 []	2 []	0 []	0 []	41
23. Does your child eat well If less than before - Does he/she require persuasion and help with meals	3 []	1 []	2 []	0 []	0 []	42
	Yes 2 []	No 1 []				
24. Does your child get upset when you leave him/her with another adult	0 []	1 []	0 []	2 []	3 []	43
25. Does he/she seem afraid of, or avoid new things	0 []	1 []	0 []	2 []	3 []	44
26. Does your child take good care of toys, books or games	3 []	1 []	2 []	0 []	0 []	45
27. Does he/she seem shy or afraid around strangers	0 []	1 []	0 []	2 []	3 []	46
28. Does your child seem afraid to leave the house <u>with</u> you	0 []	1 []	0 []	2 []	3 []	47

Thank you for completing the above.

Now finally

PARENTS RESPONSE

As a parent of a child who has recently been in hospital you are in an excellent position to comment on how the experience did or did not meet your expectations, and also to comment on how the health care team could change aspects of care to meet individual needs.

29. Overall/

Overall, concerning the care and attention you and your child received before admission do you feel

- 1. Very dissatisfied 1 []
- 2. Dissatisfied 2 []
- 3. Satisfied 3 [] 48
- 4. Very satisfied 4 []

30. If you felt dissatisfied with any aspect of preparation and attention before your child's admission - please explain what caused you to feel this way.

.....
.....
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31. If you felt satisfied with preparation could you please explain what aspects of this care were especially helpful.

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.....

32. Overall, concerning the care and attention you and your child received **during the time of admission**, do you feel;

- 1. Very dissatisfied 1 []
- 2. Dissatisfied 2 []
- 3. Satisfied 3 [] 51
- 4. Very satisfied 4 []

33. If you felt dissatisfied during your child's admission could you please explain what aspects of care you felt dissatisfied with.

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34. However, if you felt satisfied with the care and attention your child and you received while in hospital, please explain what you found especially helpful, or impressed you.

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35. Finally/

35. Finally as a result of your recent experience, if you know a family whose child was due to come into hospital what information do you think they should have? How do you think they could best be prepared for the experience

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Please comment as freely as you wish

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APPENDIX 2 Individual Item Analysis-

Contents.

Table 1	Previous experience of stress
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Pre-Admission Data

Table 1. Previous experience of stress

<u>Distressing Life Events</u> <u>During 1 year Pre-Admission</u>	<u>No events</u>	<u>Distress</u>
experimental Group	25 (83.3%)	5 (16.6%)
control i	24 (80%)	6 (20%)
control ii	22 (73.3%)	8 (26.6%)

chi-square=0.934

p=ns.

Table 2 . Age and exposure to stress. N=59

<u>Age and Distressing Life Events.</u>	<u>No Events</u>	<u>Distress</u>
<5yrs	33	13
5-7yrs	38	6

chi-square=2.07

p = n.s.

Table 3. Manifest anxiety - pre-admission.

N=59

<u>Group</u>	<u>No Anxiety shown</u>	<u>Did show anxiety</u>
Experimental	15 (88.2%)	2 (11%)
Control i	13 (72.2%)	5 (28%)
Control ii	12 (50%)	12 (50%)

chi-square- 12.2

p =0.0318

Table 4. Age and manifest anxiety.

N=59

<u>Age</u>	<u>No Anxiety shown</u>	<u>Did show anxiety</u>
<5yrs	23 (69.7)	10 (30.3)
5-7yrs.	17 (47.2)	9 (25%)

chi-square= 12.35

$p = 0.03$

Table 5. Admission arrangements.

<u>Group</u>	<u>No problems</u>	<u>Significant problems</u>
experimental	16 (53.3%)	14 (46.6%)
control i	11 (36.6%)	19 (63.3%)
control ii	10 (33.3%)	20 (66.6%)

chi-square=4.64

$p = ns$

The above table was then cross-tabulated with family size variables:

Table 6. Admission arrangements and family size.

<u>Family size</u>	<u>No Problems</u>	<u>Significant Problems</u>
only child	17 (94.4%)	1 (5.6%)
two children	12 (24%)	38 (76%)
Three - four children	5 (33.3%)	10 (66.6%)
More than four	3 (42,9%)	4 (57.1%)

chi-square =15.297

$p = 0.0016$

Table 7. Sibling adjustment.

N = 59

<u>Group</u>	<u>No adverse effect</u>	<u>Some difficulties</u>
experimental	10 (62.5%)	6 (37.5%)
control i	13 (68.4%)	6 (31.6%)
control ii	17 (70.8%)	7 (29.2%)

chi-square = 2.0

p = ns

Table 8. Parent report of change in child's behaviour pre-admission

N = 59

<u>Group</u>	<u>No change reported</u>	<u>Change reported</u>
Experimental Group	14 (82.4%)	3 (17.6%)
Control i	15 (83.3%)	3 (16.6%)
Control ii	20 (83.3%)	4 (16.6%)

chi-square-

p = ns.

Incidence of Maternal Anxiety and age of the child:

Table 9.

<u>3yrs - 5yrs.</u>		<u>5yrs - 7yrs.</u>	
<u>Mean</u>	<u>6.413</u>	<u>Mean</u>	<u>3.886</u>
<u>Std. Dev.</u>	<u>5.867</u>	<u>Std. Dev.</u>	<u>3.258</u>
<u>Std. Error</u>	<u>0.865</u>	<u>Std. Error</u>	<u>0.491</u>

p = ns

Table: 10 Parent coping - pre-admission. "things getting on top"

<u>Group</u>	<u>Not at all</u>	<u>More than usual</u>	<u>Much more than usual</u>
experimental	15 (50%)	12 (40%)	3 (10%)
control i	26 (86.6%)	4 (16.6%)	0 (0)
control ii	17 (56.6)	11 (36.6%)	2 (6.6%)

chi-square-10.5

p - 0.031

Table 11: Relationship between age and upset during transfer to operating theatre.

<u>Age</u>	<u>calm</u>	<u>some crying</u>	<u>very upset</u>
<5yrs	26 (56.5%)	15 (32.6%)	5 (10.9%)
5yrs-7yrs	40 (90.9%)	3 (6.8%)	1 (2.3%)

chi-square-15.3

$p = 0.0015$

Table 12. Induction of anaesthesia

<u>Group</u>	<u>Complete co-operation</u>	<u>mild resistance</u>	<u>extreme resistance</u>
experimental	16 (53.3%)	8 (26.6%)	1 (3%)
control i	9 (30%)	21 (70%)	2 (6%)
control ii	13 (43.3%)	13 (43.3%)	6 (20%)

chi-square-18.09

$p - 0.0076$

Table 13. Parent expectation of the child during hospital care.

<u>Group</u>	<u>Expects change</u>	<u>No change expected</u>
experimental	15 (50%)	15 (50%)
control i	10 (33%)	20 (66%)
control ii	8 (28%)	22 (72%)

chi - square =7.24

$p = ns$

Table 14. Parent expectations following transfer home.

<u>Group</u>	<u>Expects change post-admission</u>	<u>No change expected</u>
experimental	22 (73.3%)	8 (26.6%)
control i	19 (63.3%)	11 (36.6%)
control ii	6 (53.3%)	14 (46.6%)

chi-square = 2.58373

$p = ns.$

Table 15. Parent expectation and age of the child.

<u>Age</u>	<u>Expects change</u>	<u>No change expected.</u>
3-5yrs.	30 (65.2%)	16 (34.8%)
5-7yrs.	27 (61.4%)	17 (38.6%)

chi-square-0.02

p=ns.

Parent perception of how the child coped overall with the experience:

Table 16 Parent reports of child coping.

<u>Group</u>	<u>Coped well</u>	<u>Rather upset by the event</u>
experimental	17 (56.6%)	13 (43.3%)
control i	23 (76.6%)	7 (23.3%)
control ii	21 (70%)	9 (30%)

chi-square-4.19803

p=ns

Table 17. The relationship between age and child coping.

<u>Age</u>	<u>Coped well</u>	<u>Rather upset by the event</u>
<5yrs.	32	14
5yrs-7yrs.	29	15

chi-square = 0.14

p = ns

Table 18 Group and positive change after transfer home.

<u>Group</u>	<u>Positive changes</u>	<u>No changes</u>
experimental	9 (30%)	21 (70%)
control i	1 (3.3%)	28 (93.3%)
control ii	16 (53.3%)	14 (46.6%)

chi-square-19.6

p 0.0006

Table 19. Positive change and the relationship with age of the child.

<u>Age</u>	<u>Positive change</u>	<u>No change</u>
<5yrs	17 (37%)	29 (63%)
5-7yrs	9 (63%)	35 (79.5%)

chi-square-4.19

p = ns.

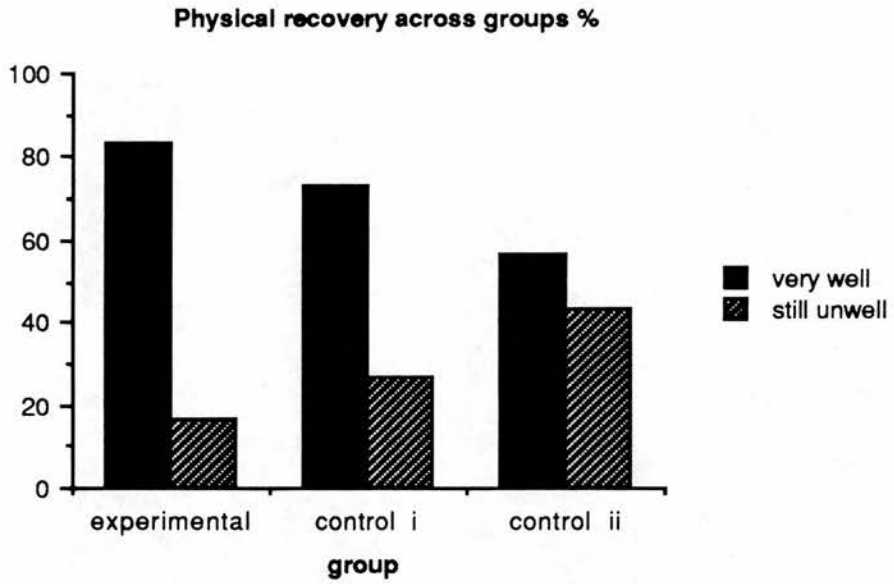


Figure 1. Physical recovery two weeks after surgery:

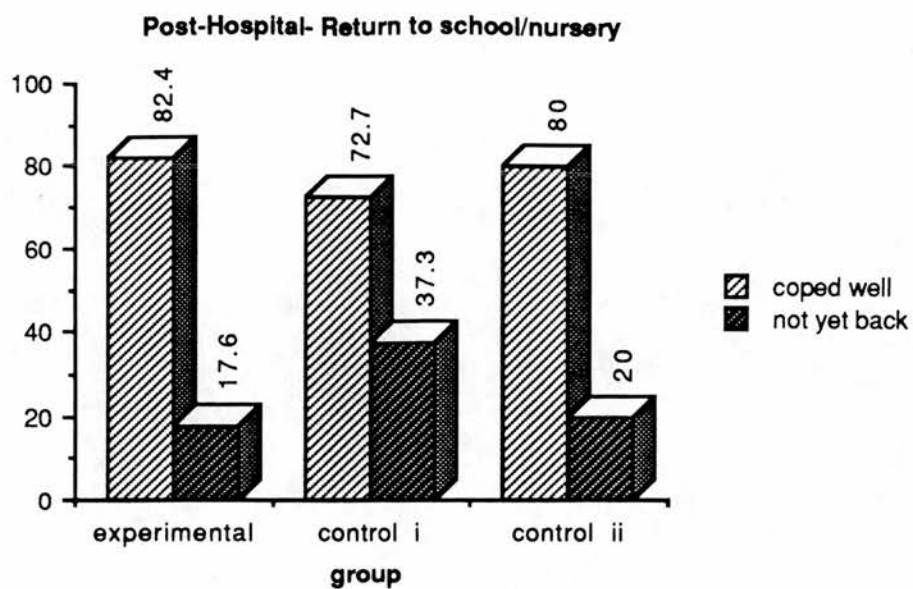


Figure 2. Child's Integration to routine activities.

APPENDIX 3.

[Bold font denotes questions asked in Child Responses]

The following questions, which are collated for ease of reference, are derived from the range of five research instruments used in this study (appendix 1).

1. Did your child ask questions about hospital? if yes, please list the things she/he wanted to know.
2. Did your child appear anxious about coming into hospital? if yes, How did this anxiety show.
3. Did you talk with your child about hospital? if yes, please describe the things you talked about
4. Did you notice any change in your child's behaviour immediately after s/he knew about hospital? if yes, please describe the changes you noticed.
5. Has this planned admission brought about any change to the family routine? if yes what are the changes.
6. Do you expect your child's behaviour to be different in any way during the time in hospital?
If yes, please describe in what way.
7. When your child is in the ward, do you expect to take part in his/her care?
If yes, please describe what you expect to be doing.
8. Can you describe what you expect of the hospital experience in the way of:
 - i. Co-operation between parent and nurse when caring for your child and
 - ii Information and support from the staff.

9. How do you feel now about your child's admission to hospital for this planned operation?

10. Are there any comments you wish to make about your own feelings or health now?

11. Can you recall how you felt when doctor first suggested admission to hospital for your child?

12. How do you expect your child to cope with the experience of admission and surgery?

13. Do you expect your child's behaviour to be different in any way when she/he returns home?

If yes, please describe the changes you might expect.

14. Have you felt any differently in the last few days in relation to eating, sleeping or general coping with things? If yes, please comment on how you feel.

15. Do you notice any changes for the better in your child's general health, for example, hearing, and speech, since she/he came home?

16. How do you think your child coped with the overall hospital experience?

Four category response offered: Coped well - no ill effects

Upset by the Event

Very Upset by the Event.

Other response - please describe.

17. How do you think your child has recovered physically, from the operation?

18. Are there any aspects of your child's care which you feel you need advice about since coming home?

19. Overall, concerning the care and attention you and your child received **before admission,**

do you feel :-

Very Dissatisfied

Dissatisfied

Satisfied

Very Satisfied

Please comment as you wish.

20. Overall, concerning the care and attention you and your child received **During the time in the ward,** do you feel:-

Very Dissatisfied

Dissatisfied

Satisfied

Very Satisfied

21. Finally, as a result of your recent experience, if you know of a family whose child is to be admitted to hospital, how do you think they could be prepared for the event?