

**THE EMERGENCE OF
NEGOTIATED FAMILY CARE IN
INTENSIVE CARE
A GROUNDED THEORY APPROACH**

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Abstract

This thesis describes a qualitative enquiry into the experiences of families visiting an adult intensive care unit (ICU) during a critical illness of a family member and nurses' perceptions of families in this environment. A Grounded Theory approach was taken. Nine families (12 adults, 12 young people) with a family member in intensive care and twenty intensive care nurses in five focus groups contributed their experiences to the study through group interviews.

Families described the admission of a family member as a traumatic event. The core experiences of families which emerged in the study revolved around uncertainty. Drawing on Davis' (1963/1991, 1966) concepts of 'clinical uncertainty' and 'functional uncertainty' a number of strategies families and young people developed in dealing with the situation were identified. 'Clinical uncertainty' captures the unknown and unknowable aspects of critical illness. The 'Functional uncertainty' category emerged later in the research process and brings to light management of information disclosure for functional gain as a communication strategy. Functional uncertainty was identified in communications between nurses and families and between parents and children within families. Moreover, young people used the same 'functional uncertainty' strategy when disclosing information to peers within the school environment.

'Keeping normality in life' and 'fishing for information' and the associated strategies were identified as direct responses of young people to clinical and functional uncertainty. The strategies identified provide new insights into how young people process a critical illness event in their families. This emphasises the importance of listening to young people's voices and the need to include young people in future studies.

'Nursing in public' emerged as an overarching theme within the data from nurses' interviews. The contrasting interests of nurses and families in the context of critical illness became evident when open visiting policies were discussed. The promotion by policy makers and nursing scholars of a patient centred health care service and thus the implicit integration of families into care challenges nurses to adapt their working practices. Whilst this study provides evidence for the importance of integrating families into care it also shows the needs of nurses are in danger of being marginalised.

Respecting the needs of families and nurses the question becomes how best to balance the competing needs of both groups. It is suggested that a 'partnership in care' approach which is firmly based on negotiations between nurses and families under the leadership of nurses will allow for the emergence of family care in intensive care, to the benefit of patients, families and nurses.

Declaration

I hereby declare that this thesis has been composed by myself and that the research on which is reports is my own work.

Susanne Kean

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GLOSSARY

A&E	Accident and Emergency, receiving unit in hospitals.
Aneurysm	Balloon-like swelling in the wall of an artery, an aneurysm in the brain can cause cerebral haemorrhage and lead to either brain damage or death.
Arrhythmia	Deviation from the normal rhythm of the heart. In its severe form (fibrillation) can cause death.
Aye	Scots for 'yes'.
Cystic Fibrosis	Or CF, is a genetic disease that affects cells of the exocrine glands, hence the production of thick mucus.
ECG	Electrocardiogram - a recording of the electrical activity of the heart.
Gastric ulcer	An ulcer of the stomach caused by acid, pepsin and bile on the stomach lining.
Haemorrhage	Bleeding
HDU	High Dependency Care Unit
ICU	Intensive Care Unit
Inotropes	Inotropes are agents that increase the hearts ability to contract.
ITU	Intensive Therapy Unit, often used interchangeably with ICU.
Myocardial Infarct or MI	Death of a segment of heart muscle, layman's term: heart attack.
Neuro	Short for Neurology, the scientific study of the nerve system.
Neonates	Infant at any time during the first four weeks of life.
O ₂ saturation	Measures the oxygen saturation in the blood, can be done with an oximetry probe which is a photometric measurement and therefore non-invasive.
Obs	Short for observational data such as heart frequency, blood pressure, ventilator parameters, volume intake and output and

	so on, observational data are recorded on an hourly basis in ICUs.
Peritonitis	Inflammation of the peritoneum – lining of the stomach.
Scan	Examination of any body part using ultrasonography, computerised tomography (CT) or magnetic resonance imaging (MRI).
Sedation	Is an induced state of sleep or rest through drugs.
Stroke	Apoplexy, a sudden weakness often on one side of the body, caused by a disruption of bloodflow in the brain.
Tidal volume	The volume of air inhaled and exhaled at each breath, can be manipulated in ventilated patients.
Tracheostomy	Surgical hole in the trachea, either to relieve an obstruction or as a route for prolonged ventilation.
Vasopressors	Vasopressors are groups of agents that produce vasoconstriction which increases aortic diastolic blood pressure and cerebral and coronary perfusion. This results in a rise in blood pressure.
Wee	Scots for 'little', 'small'

CHAPTER 1

Introduction

Introduction

The following work describes a qualitative enquiry into the experiences of families in adult intensive care units (ICU) during a critical illness and nurses' perceptions of families within this environment. A Grounded Theory approach was used.

The original motivation for this study was my own experiences as a nurse of families in intensive care units in German university hospitals. Over a number of years I observed families struggling to understand what had happened to them during a critical illness. The nursing staff's exclusive focus on the patient resulted too often in a failure to support families through these difficult times. In particular, children's experiences with critical illness were hidden from nurses since they were not allowed to visit. Parents' reports of their children's and their own distress in dealing with the multiple demands of a critical illness on their family unit left me wanting to understand in more detail how families processed critical illness.

Importance of the study

In ICUs, the critically ill patient constitutes the primary focus of health care professionals. At the same time there is an assumption in the nursing literature that the responsibilities of nurses in ICU go beyond the time-sensitive and technological work with patients and include caring for distressed families (e.g. Walters 1995, Chesla 1996, Chesla and Stannard 1997, Leske 1998, DeJong and Beatty 2000, Washington 2001, Williams 2005). However, the lack of evidence of nursing interventions in the literature suggests that family care in ICU may not be happening.

Leske and colleagues (1998) point out that 'the purpose of nursing theory is to describe the domain of nursing science' but that nursing theorists have seriously underestimated the impact of the family on the health of individual family members and the impact of

illness on the family as unit. As a result, there is a paucity of conceptual models that encompass family phenomena in nursing.

Similarly, Segaric and Hall (2005) identify a family nursing theory-practice gap which results from a lack of conceptual clarity in relation to family, family nursing and health. This gap makes it difficult to develop a family nursing theory that is able to guide practice. Conceptual clarity is critical in a theory which describes empirical reality in abstract terms and can lead practice development. Not surprisingly, the significance of theory is related to its 'relevance, applicability and adaptability to practice realities' (Segaric and Hall 2005). I concur with these authors when they argue that:

'Academics who develop theories, models and research findings and expect practicing nurses to apply such knowledge rarely take into consideration the complexity of relationships with families and patients from nurses' and clients' perspectives, as well as nurses' use of relational and tactic knowledge. Research approaches are necessary that obtain the perspective of all persons ultimately affected by family nursing – nurses, patients and family members' (Segaric and Hall 2005:216).

The importance of developing a relational family nursing practice becomes apparent when one considers the changes in health care policy which have shifted emphasis from the acute hospital setting to the community. These policy changes were set in motion with the Community Care Act 1990 and its deliberate inclusion of families as care givers (e.g. Whyte 1997a, Wasoff and Dey 2000, SEHD 2005, 2006a, 2006b, 2006c) but are undermined by the identified lack of knowledge in families caring for what are often still severely ill patients at home (Levy 2004, Foster and Chaboyer 2005).

In drawing on the perspectives of families, young people in families and nurses this work seeks to further understanding of an otherwise little understood area, namely the experiences of families in intensive care units (ICU) during a critical illness and nurses' perceptions of families within this environment in the context of the interface of the family and nursing system within the health care system (e.g. Robinson 1996, Kirschbaum and Knafl 1996, Chesla and Stannard 1997, Vaughan-Cole 1998).

The study

The purpose of this study is to advance understanding and gain new knowledge in the care of families in ICU settings and contribute to a family-derived theoretical framework for the nursing of families. The approach taken is one of interviewing families and nurses as groups, which allows tapping into the social networks participants live and work in. Given the importance of the nurse-family interface, nurses' perceptions of families are of interest - since it is this group of professionals who will implement any future family interventions.

The context

The study took place within the context of a NHS Hospital Trust in Central Scotland. The hospital in question is a teaching hospital. The unit was, at the time of the study, classified as a level 3 unit and had only intensive care patients.

Recruitment was confined to this one unit and families were recruited after their family member had been in ICU for at least three days and was stable. The study represents a substantial grounded theory in one particular area of nursing.

Structure of the thesis

In Chapter 2 the literature review aims at 'setting the stage' (Charmaz 2006) for the interpretation of data in later chapters which also contain references to research literature as appropriate. As such, a systematic initial literature review was not attempted. Instead, key aspects as they relate to my study, my professional background and awareness of the area are acknowledged.

In Chapter 3 a detailed discussion is offered on methodological issues pertaining to the study. The background of the study, methodological and theoretical position in relation to Grounded Theory, General Systems Theory, Cybernetics, Focus Groups and research with families and groups are addressed. Data generation, management and analysis procedure are discussed as they relate to Grounded Theory.

The way in which this study was conducted is explained and discussed in Chapter 4. In this chapter the process of data collection, theoretical sampling and analysis of data are described in detail.

Chapter 5 introduces the participating families in some detail. Families are introduced visually using Genograms and written family profiles using the *Calgary Family Assessment Model (C-FAM)* (Wright and Leahey 1994, 2000, 2005). The C-FAM is a useful tool for understanding how families are structured, interact with each other and function in relation to each other during critical illness.

Chapters 6, 7 and 8 offer a full account of the findings and the emerging major themes. In Chapter 6 the theme of ‘clinical and functional uncertainty’ emphasises the core experiences families go through during a time of critical illness. Clinical uncertainty was evident from the onset of critical illness, while functional uncertainty emerged slightly later in the process and was a means to manage the critical illness situation. Functional uncertainty was evident in interactions between health care professionals and families and in interactions within families.

Chapter 7 outlines young people’s strategies in response to critical illness in their families. The strategies of ‘keeping normality in life’ and ‘fishing for information’ brought to light the activities young people developed in response to ‘clinical and functional uncertainty’. Although there are power asymmetries in families, young people were not passive but actively constructed and co-constructed their own and other’s experiences during a time of critical illness. This is reflected in their various strategies for accessing information and positioning themselves within the ongoing illness situation in their family.

‘Nursing in public’ is the major theme that emerged in relation to nurses’ experiences with families in ICU. Chapter 8 outlines the context and different dimensions of this theme. Drawing on the insights from the family data the interplay between both groups in the same social space is further developed in this chapter.

Chapter 9 is the concluding chapter and suggests a partnership in care approach. This approach is firmly based on negotiated boundaries between the family and nursing system. Within this approach nurses are envisioned as taking a leadership role in ICU family care.

CHAPTER 2

Literature Review

Introduction

The intention of the following literature review is to examine the literature as it relates to families' critical illness experiences, the nursing of families during this time and the understanding of children within the context of family. The literature review will 'set the stage' (Charmaz 2006) for the interpretation of data in later chapters. As such, a systematic review of the literature is not attempted. Instead the literature review focuses on key aspects as they relate to this study, acknowledging my professional background and awareness in this area. Naturally, the bodies of literature that are of interest go beyond the boundaries of nursing and include work from sociology (medical, family and childhood) and medicine which links to intensive care nursing in relation to critical illness in families.

Search strategy

Material for this chapter was identified through electronic search engines such as CINAHL, PubMed, Medline and Social Science Citation Index. Search terms included family, family nursing, critical illness, critical care, intensive care, children and childhood in various combinations. Additional material was identified through references in articles and books. Some articles were retrieved using the University of Edinburgh Library Inter Library Loan service while others were downloaded through various internet services (e.g. Street Wise, Blackwell Synergy, NHS e-Library).

Families' experiences in intensive care

The primary concern of health care professionals in intensive care units (ICU) is the life-threatening pathophysiological state of the patient. Consequently, the focus is on stabilisation and survival of this patient. Yet, a number of nursing scholars describe the admission of a family member to ICU as a crisis situation not only for the patient but also for the family (e.g. Leske 1986, Coulter 1989, Freichels 1991, O'Malley et al. 1991, Mendonca and Warren 1998). This particular argument is based on the

assumption that there exists reciprocity between the individual's health and the health of the family (e.g. Titler et al. 1991, McCubbin and VanRiper 1996, Hupcey 2000, Denham 2003).

It is further acknowledged in the nursing literature that the responsibility of nurses working in ICU goes beyond the time-sensitive and technological nature of their work and includes caring for distressed family members (e.g. Walters 1995, Chesla and Stannard 1997, Mendonca and Warren 1998, DeJong and Beatty 2000, Washington 2001, Williams 2005). However, as Benner and colleagues (1999) point out, caring for distressed family members has not been a traditional part of nursing during such a life crisis. Nursing interventions in this area are often noticeable by their absence and Benner and her colleague's argument is further supported by the lack of research into families' experiences in ICU. Research regarding the family needs of a critically ill patient is the one exception in this domain that has received considerable attention over past decades. In particular one instrument, the *Critical Care Family Needs Inventory* (CCFNI), has been extremely influential in shaping a research focus and consequently current family related knowledge in intensive care nursing.

Therefore, it is necessary to briefly outline over two decades of family needs studies in order to understand the impact of needs research on nursing knowledge. This also hints at paths not taken in nursing research due to the exclusive focus on needs.

Family needs research

In 1979 Nancy Molter, a North American scholar, carried out an exploratory, descriptive study that established the basis for the later developed CCFNI instrument. Following a literature review and a survey of 23 graduate students, she developed a list of 45 needs statements on a 4-point Likert scale before interviewing relatives of critically ill patients. The result is in the form of a ranking list of needs from most important to least important. Molter's (1979) research was based on the assumption that an unresolved family crisis may affect the outcome of the patient's illness. Although she aimed at identifying family needs during a family illness crisis, the needs list was developed without any family involvement and therefore lacks a theoretical family framework.

Critical Care Family Needs Inventory

Jane Stover Leske (1986) took up Molter's previously developed instrument, randomly rearranged the needs statements in cooperation with Molter and added one open-ended question in an attempt to detect any new needs. Her study aimed to identify needs of family members of critically ill patients during their ICU time and to compare results with those of Molter's study. The sample size in Molter's (1979) study consisted of 40 relatives and represented individual responses after the patient's transfer from ICU, while in Leske's (1986) study 55 family members of 20 patients were interviewed giving a mutually agreed response during the patient's time in ICU.

Leske then carried out a *t* test in an attempt to compare and detect any statistically significant differences between the two studies. This procedure is highly questionable since the studies differ in a number of variables such as time of data gathering, form of response, sample size, (most likely) patient variables and age of family members interviewed. These variables are significant and have been partially addressed by other researchers as important differences in understanding the ICU experience of families (e.g. Rodgers 1983, Spatt et al. 1986, VanHorn and Tesh 2000, DeJong and Beatty 2000).

The result of this study became known as the *Critical Care Family Needs Inventory* (CCFNI) which lists 45 family member's needs of a critically ill patient according to their significance on a 4-point Likert scale from most important to least important. An example is displayed in Table 1. Reliability, readability and content validity of the instrument has been established and reported in a number of studies (e.g. Norris and Grove 1986, Leske 1991, Macey and Bouman 19991, Rukholm et al. 1992).

Table 1: Examples of identified needs in CCFNI studies

NEEDS	AUTHOR	YEAR
<ol style="list-style-type: none">1. To feel there is hope2. To feel that hospital personnel care about the patient3. To have the waiting room near the patient4. To be called at home about changes in the condition of the patient5. To know the prognosis	Molter	1979
<ol style="list-style-type: none">1. To feel there is hope2. To have questions answered honestly3. To know the prognosis4. To know specific facts concerning the patient's progress5. To have explanations given in terms that are understandable	Leske	1986
<ol style="list-style-type: none">1. To have questions answered honestly2. To be assured that the best care is being given to the patient3. To feel there is hope4. To feel that the hospital personnel care about the patient5. To know specific facts concerning the patient's progress	Norheim	1989

Needs studies using the CCFNI span over two decades and the results are, perhaps not surprisingly, similar. There are a number of needs that rank persistently high across studies. For example, to feel there is hope, to be near the patient, to receive information about the patient every day, to have questions answered honestly and to feel that staff cared about the patient are among these high-ranking needs (e.g. Leske 1986, 1992, Norheim 1989, Freichels 1991, Quinn et al. 1996a, 1996b, Gelling and Prevost 1999, Kosco and Warren 2000). These needs can be sorted under a number of headings relating to assurance, proximity, information, comfort and support (Leske 1992). Sorting individual needs into conceptual categories helps to shed some light on the family's experience in ICU and hints at possible interventions.

In the context of my research, Coulter's (1989) study is of particular relevance. While she is focusing on needs of family members with a patient in ICU, her approach is qualitative in nature and situated in the United Kingdom (UK). Coulter's grounded theory analysis indicates a more complex scenario than suggested by CCFNI studies and therefore furthers understanding of what the themes identified in CCFNI studies actually mean. The need 'to feel there is hope' can serve as example. While it is important to identify this need, the meaning of it remains unclear in all CCFNI studies.

Coulter (1989), in contrast, points out that hope has two dimensions; firstly, generalised hope that refers to broad and abstract emotions which aim to protect against despair and secondly, particularised hope that is directed to a more specific outcome rooted in the belief that things will improve.

Wilkinson (1995) provides another example of a qualitative UK based study into six ICU family member's self-perceived needs. She replicated Coulter's earlier study in that she too used a grounded theory approach. Not surprisingly, there is some overlap in terms of findings. Both identified the shock of an emergency admission, the need for information and social support, the need to be near and to retain hope as major theoretical categories in their data. Wilkinson (1995) does not report data saturation thus the strength of her findings must be questioned.

The expression of feelings of hope, anxiety and uncertainty by families while describing their ICU experience during the initial period of critical illness is a recurrent theme across qualitative studies (e.g. Coulter 1989, Rose 1995, Wilkinson 1995, Hupcey and Penrod 2000). Families are constantly looking for clues from patients and nurses in an attempt to understand what is going on and which way the situation might develop (Rose 1995). Therefore hope can be linked to information needs. It is here that the limitations of CCFNI studies once more become evident. In acknowledging that a need exists, which is what CCFNI studies do, the meaning of a need and possible interventions to satisfy this need remain unknown. In the context of information provision to families nursing research has so far failed to determine who needs what when and what kind of information is required. This situation is particularly acute in relation to children and young people. I was, for instance, unable to identify a study that examined information needs of these age groups with a critically ill parent in ICU. There is recent research determining availability of information to either adult relatives (Hughes et al. 2004) or children (Vint 2005a, 2005b) visiting an ICU. Both studies are of particular relevance to this study since they are UK based and in the case of adults concluded that there is a huge variation nationally over the amount and quality of information available, while in the context of children very little information exists that could be handed out.

Additionally, Norheim (1989) questions the underlining assumption of most CCFNI studies that for all family members needs are of equal importance. She examined needs of family members during the intraoperative period of patients undergoing heart surgery. In this study the family group was divided into spouses and relatives. Spouses rated eight needs as more important than other relatives did (i.e. visit at any time, having a friend nearby for support) thus indicating differences in needs within families. Gender is another dimension. Spatt and colleagues (1986) found that men tended to rate needs as slightly less important than women did. However, no replication studies could be located, suggesting that this is another research path yet to be taken.

A number of CCFNI studies suggest differences in perception of family needs between nurses and families. This research focus was first formulated and investigated by Norris and Grove (1986). Their argument was that nurses' interventions are guided by their perception of family needs in a critical care situation. They reduced Molter's original questionnaire to 30 items. Content validity and reliability for this new instrument was reported. Perhaps not surprisingly, nurses and family members' assessment differed on a number of needs. Information, for example, was one of the high ranking family needs. Nurses in this study however underestimated the amount and depth of information needed by families.

Norris and Grove's study triggered similar research with similar results that focused either on comparing family members and nurses (e.g. Dockter et al. 1988, Jacono et al. 1990, Forrester et al. 1990, Kleinpell and Powers 1992, Quinn et al. 1996a, 1996b) or on family members, nurses and physicians' needs perception (Gelling and Prevost 1999). These studies suggest that successful interventions with families have to take account of nurses' perceptions of families and provide a rationale for including nurses' perceptions in this study.

In summarising, it is evident that more than two decades of needs research, mainly quantitative in nature and based on the CCFNI, has had a considerable influence on the focus of research and consequently on contemporary knowledge in intensive care nursing. This conclusion is further supported by the fact that whilst the original

instrument was developed in North America, it has been used in other parts of the world, for example, Spain (Zazpe et al. 1997), Australia (Burr 1998), Hong Kong (Lee and Lau 2003), Sweden (Takman and Severinsson 2004) and Belgium (Verhaeghe et al. 2005). It was also revised for use in emergency departments (Redley and Beanland 2004). In interpreting the findings of these studies for practice, caution has to be exercised for a number of reasons. Limitations include the instrument's lack of a theoretical family framework, the differences in defining 'family' or 'relative' across studies which in turn compromises comparisons, small sample sizes across many studies and hence the validity of their statistical analysis (see also Holden et al. 2002), the exclusion of children from family research in this area, its failure to explain what identified needs actually mean and its failure to identify effective family oriented interventions, a point also criticised by others (Simpson 1989, Hupcey 2000).

When reading the small number of qualitative studies available it becomes increasingly clear that a specific need focus captures only a small part of the whole families' ICU experience.

Impact of critical illness on families

CCFNI studies highlight family needs during a critical illness and thus are important as part of an overall understanding. It is however the small number of qualitative studies enhancing the depth of current understanding of families' experiences in ICU. Across these studies there is a striking difference in their conceptualisation of 'family'. In some instances the term 'relative' is used which translates into a research focus on adult family members. Other researchers do use the term 'family' and their studies may or may not include children. Some researchers use both terms interchangeably. In essence, what we are left with are two strands of research in relation to family which reflect different aspects of families' experiences during critical illness and a conceptual 'muddle' as to what constitutes family in a critical illness context.

A number of studies suggest that an admission to an ICU has an immediate impact on daily family life patterns and thus on family life in general. This is evident in Hupcey and Penrod (2000) grounded theory study where 'going it alone' emerged as a core category. In this study the majority of spouses were interviewed while their partner

was still in ICU. The impact of a critical illness on the family unit was evident in a shift of responsibilities to the well spouse in relation to parental, household, financial and health related decision making. The burden of this sole responsibility was felt despite support from family and friends. In trying to meet the needs of both parties, particularly parents of (young) children faced the conflict of being either with the critically ill spouse or with the children. In this context the need 'to be reassured (by nurses) that it is alright to leave the hospital for a while' expressed by spouses in Norheim's (1989) study finally gets some meaning. Outlining the role of a *family advocate* Washington (2001) describes the supply of pagers to families waiting for surgery outcomes or in a ICU waiting room as a possible intervention. This allows families the freedom to meet some of their own needs while being reassured that they will be updated with any occurring changes.

Communication between health care professionals and families but also between family members is another key concern. The lack of communication concerning feelings emerged as a core theme in a phenomenological study by Titler and colleagues (1991). Individual family members did not talk about their own feelings to each other leading to very different interpretations of what the other thought the ICU experience must have been for the partner or children. Consequently, the lack of communication effectively inhibited individual family member's understanding of the ICU experience in the context of their family. It is perhaps not surprising that Jones and colleagues (2004), using a quantitative approach, found a high incidence of psychological distress in patients and relatives even six months after the ICU experience.

Withholding information in an attempt to protect significant others such as ill spouses or children is another aspect of communication that emerged in some studies. In Hupcey and Penrod's (2000) study the well spouse tried to protect the partner from any information thought to be distressing thus increasing their own burden.

In Titler and colleagues (1991) study parents withheld information about the critically ill parent in an attempt to protect children from anxiety. Lewandowski (1992) points out that parents and nurses too often hold the view that children are too young to

understand without considering the consequences for the child involved. This failure to recognise the specific needs of children with a family member in ICU can result in feelings of isolation (Baker et al. 1988) as these children are left to imagine what is going on in ICU without any support to make sense of the situation.

The importance of allowing children to visit their ill parent in ICU emerged in Craft and colleagues' (1993) study. In this study, which is identical with Titler and colleagues (1991) but reports on a different aspect of their data analysis, children (age range 7 – 18 years) described their emotional turmoil and the impact of the disruption to their daily life patterns brought on by the critical illness of a parent. Visiting their parent and seeing for themselves was one coping strategy mentioned by these children. The reasons why nurses in the UK restrict children visiting their parent in ICU are not clear and, as Clarke (2000) argues, are not based on research but on individual views of nurses. There is certainly a lack of research here but those few studies that exist suggest that this could be an interesting family nursing intervention (e.g. Craft et al. 1993, Clarke 2000, Clarke and Harrison 2001). It seems to be self-evident that any intervention with children has to be age appropriate (Baker et al. 1988, Kean 2001a) and that visiting a parent in ICU needs careful preparation.

While the above studies investigated the impact critical illness has on families the next section examines research that looked at a different aspect of critical illness in relation to family.

Experiences of families in ICU

The following studies focus on adult family members and their experiences with critical illness. The questioning in these studies is narrower in that they focus on the experience of a family member in relation to their experiences within the ICU environment and thus leave the family in the background. Walters (1995), for instance, asked relatives what was going through their mind when seeing their loved one in ICU while Lam and Beaulieu (2004) were specifically interested in why family members stayed at the bedside.

Walters (1995) is one of the authors who uses 'family' and 'relative' interchangeably. His phenomenological study includes 15 female visitors visiting a critically ill family member in a large tertiary hospital in Australia. In contrast to needs studies, Walters specifically aimed at preserving the uniqueness of the ICU experience in providing an ontological understanding of the family's experience during critical illness. He uses the term 'ontology' in the sense of 'explicating the nature of people and things' (Walters 1995: 999). Following a Gadamerian hermeneutic 'being with' and 'seeing' emerged as themes from his text interpretation.

'Being with' relates to the physical and emotional presence of families and nurses with patients. It is this 'connectedness' between family member and patient that is of importance in maintaining the physical and existential bond between family members. In visiting the patient on ICU family members shared their spaces thus emphasising a connectedness that has grown over many years within families. For Walters, family provides a sense of home within ourselves and therefore reinforces our need to 'be with' our loved one during a critical illness.

'Seeing' directly feeds into this experience in that family members need to see their critically ill family member in order to create meaning from what is happening. It was their familiarity with the patient that led to an assessment influencing their perception of illness severity.

Hughes and colleagues (2005) used a grounded theory approach in eliciting nurses and relatives perception of families ICU experiences in the UK. Interestingly, some relatives felt that television (TV) had actually prepared them for the ICU experience. Nurses disagreed and argued that TV programmes led in some cases to unrealistic expectations. One example related to 'patient's waking up' in TV programmes which is nowhere near the real experience families go through when observing their loved one coming out of sedation in ICU. It was therefore not surprising that particularly families of brain-injured patients spoke of their emotional rollercoaster as the patient improved from the critical illness but was still different to the person they knew prior to the injury.

Information was another theme that featured in this study. Relatives were particularly dissatisfied by the lack of communication opportunities with physicians. The authors concluded that there was a lack of communication between staff and relatives leading at times to different understandings of the patient's situation. This finding is in line with Azoulay and colleagues (2004) study, who found that family members who had less time to receive information from physicians and did not have written information in the form of a booklet available had a poorer comprehension of the critical illness situation. Not surprisingly, Hughes and colleagues (2005) found that nurses had to repeat information for relatives a number of times before it was understood.

In relation to brain-injured patients, Lam and Beaulieu (2004) provide another piece of the picture relating to family experiences in ICU. They focused on neurological patients arguing that families in neurological ICUs undergo different experiences due to the real possibility of long-term brain damage and thus disability (Lam and Beaulieu 2004:143). Data were collected by means of participant observation and semi-structured interviews with family members. Data were analysed following the constant comparative process as described by Strauss and Corbin (1998).

The categories of 'best care' and 'connection' emerged from this analysis. 'Best care' referred to families' need to actually witness the care their loved one received in an attempt to reassure themselves that all that could be done was done for the patient. 'Information seeking', 'pitching in' and 'fitting in' were three strategies which families employed to ensure 'best care'. Information seeking refers to behaviour that enables family members to make sense of their experience and thus relates, for instance, to watching monitors as well as seeking information from health care professionals. 'Pitching in' refers to family members involvement in care activities while 'fitting in' relates to family members attempt to socialise themselves into the ICU environment so that they were 'not in the way'.

Similar to Walters' findings, the category of 'connection' in Lau and Beaulieu's study refers to 'being at the bedside' and connecting to the critically ill family member. 'Connectedness' in the later study might actually have a different urgency due to the brain injury and thus the unknown extent of its consequences. Families who bring in

photos as a means to talk about their loved one before the incident underlined their need to recall the person as they lived on in their memories which, in turn, emphasises the difference in meaning between the two studies.

In the above cases, not only can study findings be linked back to needs studies and thus illuminate previously identified needs with a level of understanding which was clearly missing from over two decades of CCFNI studies, they also provide a very different and more complex picture of families' experiences in ICU. Chesla and Stannard point towards the current failure in the care of families in stating that:

'ICUs are the domain of specialities, and decisions about a patient's care often involve as many as six or eight specialists in various body systems, but no one who specialises in family systems or in the relations between family systems and complex healthcare systems' (1997:70).

The absence of family care in ICU is perhaps not so surprising after all. In more general terms, the interface between families and nurses has been identified by a number of authors as an understudied area in nursing (Kirschbaum and Knafl 1996, Robinson 1996, Faux and Knafl 1996, Chesla and Stannard 1997, Vaughan-Cole 1998). Nursing simply lacks sufficient knowledge about families' experiences in ICU to reconceptualise intensive care nursing as a family focused health care service. This is reflected in the lack of studies addressing the topic. I therefore concur with those authors who argue that previous quantitative studies have failed to draw out the complexity of families' experiences in ICU and that it is time to explore their perception from a qualitative approach (Walters 1995, Lam and Beaulieu 2004).

In relation to families' critical illness experiences family nursing provides a number of conceptualisations for understanding families that are useful in a research context. This is the focus of the next section.

Families in nursing

The failure of family care in ICU (Chesla and Stannard 1997) is partly due to the immediate focus of health care professionals on stabilising the life threatening situation. That this specific focus is necessary in order to ensure the patient's best chances of survival is uncontested. Yet, as the previously discussed research suggests,

a critical illness is a family affair. A further reason why families do not necessarily feature in intensive care nursing can be found in the overall focus of nursing which, despite its move towards a family-centred approach in some areas, remains focused primarily on individuals (Bozett 1987). In relation to intensive care nursing, Bozett proposed that:

‘[f]amilies with adult members in intensive care units need to be assessed early in the patient’s hospitalization (within the first 24 hours) and regularly thereafter. It is best if the patient’s nurse spends a specified amount of time with the family every day at a predetermined hour, in addition to prearranged times for phone contact’ (Bozett 1987:6).

Such a family nursing approach to families of critically ill patients would allow going beyond the boundaries of the individual and addressing the needs of families.

Family nursing

The family as recipient of care is not new to nursing. In fact, during the Victorian era in 1859 Florence Nightingale envisioned in her *Notes on Nursing* nurses taking care of ‘the sick and well in their own homes’ thus picturing nurses working in the community with ill and healthy care recipients alike (Whall 1986, Nightingale 1859/ 1992, Baly 1997, Bomar 2004). Family nursing as a model originates in North America. Within the North American context there are two different groups identifiable; firstly the Canadian scholars and secondly the United States (US) scholars. Unlike their US counterparts the Canadian scholars base their approach firmly on family therapy. This is particularly evident in the work of Wright and Leahey (1994, 2000, 2005) and the group surrounding these two scholars which is based at the University of Calgary. It is here where the first ‘Family Nursing Unit’ came into existence. Families in this unit are self referred and undergo a short term family nursing therapy intervention which is simultaneously used as a learning opportunity for nursing students in their undergraduate education (e.g. Tapp et al. 1997, Bell 2001, Moules and Tapp 2003) as well as by nurses in their Family Nursing Master programme (Tapp and Wright 1996, see also for US Chesla et al. 1993). The acknowledgment of a difference in perspectives between Canadian and US scholars is further emphasised by Bomar

(2004), who in the third edition of her textbook specifically incorporates a Canadian perspective in addition to the US view of family nursing.

Hanson (2005) emphasises that family therapy theories have an influence on family nursing in the US and argues that family nursing is continuing to integrate knowledge from family therapy and family social science. In this sense, the original Canadian work is certainly evident in the work of leading US scholars but, at the same time, US scholarship differs in that their work embraces a diversity of foci including those relating to everyday nursing, public health or health promotion - as reflected in their textbooks (Friedemann 1995, Bomar 1996, 2004, Friedman 1998, Hanson and Boyd 1996, Hanson 2001, Hanson et al. 2005).

Within a European context, Whyte's (1994) research with families caring for a child with cystic fibrosis was the first study in the UK to draw on the concept of family nursing. She subsequently edited a book with the meaningful title '*Explorations in Family Nursing*' (Whyte 1997) underlining that family nursing is very much in its infancy within a European context.

Other developments in family nursing across Europe include a first German text on family nursing (Gehring et al. 2001) and a number of writings and studies drawing on concepts of family and nursing across nursing disciplines (e.g. Hammond 1995, Åstedt-Kurki and Hopi 1996, Robb 1998, Murray 2004, Kolbrún-Svavarsdottir and Sigurdardottir 2005, Latour 2005, Johansson et al. 2005).

Conceptualising family nursing

The way in which family nursing and therefore nurses' work with families is conceptualised is very similar across referenced scholars. Systems theory has been the dominant framework on which 'most, if not all, family nursing practice and theory' is based (Hartrick 1995).

Wright and Leahey (1990), for example, distinguish between two levels; family nursing and family systems nursing. Family nursing has two further dimensions in that it can either focus on the individual in the context of the family or, alternatively, focus on the family with the individual as context. Family systems nursing, in contrast,

focus firmly on the whole family as unit of care. On this level the family and the individual are viewed simultaneously through the interaction and reciprocity that exists within systems. Wright and Leahey (1990) argue that family systems nursing is the integration of nursing, systems, cybernetics and family therapy theories.

Friedemann (1989) offers a conceptualisation of family nursing on three levels. In her approach she defines firstly, the level of the individual, secondly, the interpersonal level and thirdly, the family system level. On the individual level the patient is viewed as a subsystem of the family but the focus of attention remains the individual. On the second level, nurses pay attention to the interpersonal system which is described as two or more individual subsystems in the context of their interaction. The third family systems level focuses on the whole family.

Hanson (2001, 2005) and Bomar (1996, 2004) further refine the conceptualisation of family nursing by including a fourth dimension. Their classifications comprises of firstly, family as context, secondly family as client, thirdly family as a system and fourthly, family as a component of society. 'Family as context' is identical with Wright and Leahey's (1990) and Friedemann's (1989) levels where the individual is the focus of care and the family remains the context. On the second level, 'the family as client', both scholars envision a family assessment of all family members but individuals within families still remain the focus of care. While they explicitly propose to look at all family members and not only at subsystems as suggested by Wright and Leahey (1990, 1994) or Friedemann (1989, 1995), essentially there is no difference since interventions with subsystems is implicitly included in Hanson's and Bomar's classifications as is the possibility to look at all individuals with the family as context in Wright and Leahey's and Friedemann's classification.

The 'family as a system' level is again identical with Wright and Leahey's as well as Friedemann's 'family systems nursing' level in that the 'family as systems' becomes the care recipient. It is the fourth level where families are seen as components of society that is fully explicated by Hanson and Bomar. This view is informed by Bronfenbrenner's (1979) ecological systems theory in which he outlines different 'layers' of the environment, the interaction between these layers and its components in

relation to the effect this is having on the development of the individual. In short, there exists reciprocity between families and components of their social networks such as school, church, support groups, health care systems and so on in terms of health and wellbeing or, following Bronfenbrenner's focus, their development.

Apart from the additional fourth level in Hanson's as well as in Bomar's model, there is very little difference in meaning. In working with families nurses move between foci according to the situation and their educational preparation in that they either intervene with the individual or a subgroup of the family (e.g. mother – child dyad) while the family remains the context and thus in the background. A real difference in practice terms emerges on the family systems level where the family as whole becomes the client and therefore the foreground for nursing interventions. In general, while these three presented conceptualisations do differ slightly, they have all been accepted and adopted within practice, writing and research on families in nursing.

Family nursing: generalist or specialist practice?

Closely linked to the level of intervention is the question whether family nursing is a generalist or specialist practice which, in turn, correlates with the educational preparation of nurses. On this issue Gilliss (1991) argues that the 'family as context' is a generalist practice view that can be applied throughout nursing independent of its focus (e.g. paediatric, neurology, mental health, intensive care and so on) and requires an education on a baccalaureate level, while the 'family as unit of care' constitutes specialist practice and therefore a graduate education on either Master or Doctoral level is necessary. This view is shared by other scholars in this area (Bozett 1987, Friedemann 1995, Hanson and Boyd 1996, Hanson et al. 2005, Wright and Leahey 1994, 2000, 2005, Bomar 1996, 2004).

In the context of the UK the issue is slightly different. The only formalised education on families in health and illness leading to a qualification with 'family' in its title is the Family Health Nurse (FHN) which is a project of the World Health Organisation (WHO) Europe. The WHO envisioned a new nursing role with a focus on family health and developed a conceptual framework (WHO 2000) which was then adapted for the Scottish pilot programme (Murray 2004). The Scottish Executive Health

Department, as relevant policy maker, clearly defines the role of FHNs as a 'skilled generalist role' within nursing (Macduff 2005). This pilot project is well under way and a number of evaluation research reports exist (Macduff and West 2003, 2004, 2005, Macduff 2005). It is however the case that neither the WHO FHN curriculum nor pre-registration nursing education in Scotland draws on family nursing as a guiding framework (e.g. O'Sullivan-Burchard et al. 2002).

Defining 'family'

The insight that 'families are familiar, but also elusive' (Wasoff and Dey 2000) immediately points to difficulties in defining the term 'family'. Bomar (2004) points out that 'family' is defined differently by scholars, governments or organisations reflecting the different interests of the definer in families. This is not surprising given the fact that the function of a definition is to draw boundaries around a concept in order to describe areas of intervention or practice. My focus in this section remains within health care as it relates to nursing of families. A further discussion on the definition of families is provided in chapter 3.

In relation to family nursing, a variety of authors provide a number of definitions, often reflecting their particular practice interest. Wright and Leahey (1994, 2000, 2005) famously define family as 'who they say they are'. Friedemann's definition is similar in that she states 'the family is defined as all persons an individual considers to be family' (Friedemann 1995:18). Denham defines family as 'a collection of individuals with a general commitment to the well-being of one another and who label themselves as family' (Denham 2003:227). 'A family is defined as two or more persons who are linked together by intimate association, resources, and values and consider themselves to be a family' is the definition Bomar (2004:9) offers. Similar to preceding definitions, Hanson (2005:7) advances a definition that states 'family refers to two or more individuals who depend on one another for emotional, physical, and economic support. The members of the family are self defined.'

Definitions of families in family nursing are characterised by a number of features which emphasise that firstly, families are self defined units; secondly, contemporary families do not necessarily share biological ties and thirdly, that families define

themselves through shared values, emotional connectedness and their willingness to support each other and share economic resources. While all these forms of definition embrace family diversity, Friedemann's (1995) definition also draws attention to the variation of family definitions within families and thus its subjective nature.

Family nursing defined

In an earlier paper Gilliss (1991) criticised a conceptual 'muddle' in defining family nursing. She points out that the failure to differentiate clearly between family-as-context and family-as-client of care has led to confusion as to what constitutes family nursing practice. She goes on to argue that 'family nursing should consistently address the family group throughout assessment, planning, intervention and evaluation' (Gilliss 1991:20). Bozett (1987) further underlines the contextual nature of family nursing in that circumstances and competence often dictates the level on which a nurse is able to function. He too proposes that family nursing considers the whole family in all phases of the nursing process and that family nursing is not restricted to a particular health care setting but constitutes universal nursing practice.

Significantly, and reflecting a recent trend in family nursing, Hartrick, Doane and Varcoe (2005) go further in suggesting that family nursing practice is enacted in relation with families, consequently it is not *for* but *with* families. It is their belief that relationships are the foundation of nursing practice and therefore require nurses to express and develop their relational capacity with families (Hartrick 1997, Hartrick-Doane and Varcoe 2005). A facet of relational practice is, for example, reflected in Bomar's definition when she argues that family health nursing is 'nursing actions directed towards improving the quality of family existence by strengthening and collaborating with families' (Bomar 2004:4).

In sum, family nursing is defined as nurses offering care to family groups, therefore going beyond an individual family member (Gilliss et al. 1989) and is embedded in a relational practice framework (Hartrick-Doane and Varcoe 2005). Group focus and relationality with families are thus the features which distinguished family nursing from nursing.

Family nursing research in context

Despite the long standing focus on families within family nursing research Gilliss and Knafl (1999:243) assert that ‘we may know less about families than we would wish to acknowledge.’ One prominent reason why this is the case relates to the source of information. As is evident in the literature reviewed above most research on families is based on data gathered from one family member about their family. As Fisher and colleagues (1985) argue, the methods used to collect data from families defines and limits statements made based on those data. This criticism, that researchers fail to gather data from families as units or more than one individual within a family has not only been made by family social scientists (e.g. Fisher et al. 1985) but also by nursing researchers (e.g. Gilliss and Knafl 1999, Bell et al. 2000).

It is perhaps for this reason that with a few notable exceptions (e.g. Snethen and Broome 2001, VanRiper 2003, Stalker and Connors 2004, Carter 2005) the voices of healthy children from families affected by illness still remain unheard. It is somewhat striking that families are understood and described as interrelated systems which are all affected by illness (e.g. Doherty and Campbell 1988, Craft and Willadsen 1992, Allmond et al. 1999, Wright and Leahey 2005) and yet the focus of research remains largely on subsystems within families. Logically, the inclusion of children’s voices is of paramount importance in research seeking to understand families’ experiences during critical illness.

The sociology of childhood as an academic discipline developed a specific interest in the subjective meaning of children’s viewpoints on a variety of issues (Hill and Tisdall 1997). The perceptions of children within this discipline and the approaches that were developed to hearing children’s voices are the focus of the next section.

Sociology of childhood

It is clear that an interest in families goes beyond nursing and can be found in a number of disciplines (e.g. sociology, medicine or family therapy). However, despite a focus on family issues, children within these disciplines are often overlooked. This is evident in journals on families or educational sociology where one might expect children to be the focus, and yet they remain in the background (Qvortrup 2002).

Jenks (1996) voiced a similar concern in the context of developmental psychology, while Vetere and Dallos (2003) make a comparable argument for family therapy in that they criticise practice in this area for neglecting the family as unit by focusing on adult individuals which implicitly entails an ignorance toward children's viewpoints. These points are reflected in Hill and Tisdale's (1997) criticism that many 'so-called family theories' are preoccupied with adults and therefore should correctly be called partnership or parents theories. There is some form of agreement across disciplines that in past decades children were subsumed under headings of family, household, education, gender, class and so on which in turn contributed to children's invisibility across health and social sciences (e.g. Jenks 1996, Oldman 1994a, Alanen 1994, Hill and Tisdall 1997, Kean 2001a, Qvortrup 2002, Wyness 2006).

Oldman (1994a) calls this 'familiarisation' by which he means processes that reduce children to their roles in a parent-child relationship with all its implied assumptions of emotional values, socialisation and invisibility within an essentially private institution called 'family'. Halldén (1994) makes a similar point noting that even when children are included in family research, they are rarely heard in their own right. Her critique is supported by Oakley (1994:20) arguing that 'children's studies are not rooted in the same way in the movement of children to claim their own liberation' but reflect adult beliefs about children thus effectively undermining children's voices. In relation to critical illness, the failure to listen to children can result in a situation where they feel isolated and left alone (e.g. Baker et al. 1988). With regards to sociology, it was the insight that there was general ignorance of children on a macro and micro level that contributed to the development of the sociology of childhood as academic discipline particularly during the 1990s (e.g. Hill and Tisdall 1997, Morrow 2003).

Childhood versus adulthood

Development, as viewed from the perspectives of developmental psychology and sociology, has been identified as a key concept in the analysis of childhood and children's lives (e.g. Archard 1993, James and Prout 1997, Lee 2001). In reference to its influence on childhood and child-related knowledge it was branded the 'dominant framework' (Prout and James 1997, Lee 2001) which specifically drew on the biological immaturity of children, linking it with the concept of dependency and thus

implicitly to other social aspects of children's lives. It is within this developmental perspective that childhood emerged as opposition to adulthood. James and Prout (1997) point towards the uncritical incorporation of the developmental psychological model into sociological theory, resulting in a view that children were less mature, irrational and incompetent which was remedied through a socialisation process. It is however also the case that whilst socialisation and maturation are distinguishable concepts, they are also interrelated and linked to a child's development (Handel 2006).

It is therefore, in essence, a 'human becoming' model, where children are depicted to be on a journey from 'becoming' to 'being' from childhood to adulthood (e.g. Archard 1993, Mayall 1994, Oldman 1994a, 1994b, Lee 2001, 2005). The impact of this perspective is evident in everyday discourse in reference to children's position on a biological development continuum expressed in terms like babies, toddlers, pre-school children or teenagers and so forth. Directly linked with these terms are expectations of society, teachers, parents, health care professionals and so on regarding a child's ability. Here, the biological view links with social development since different biological stages are associated with social development, for instance, interaction, play or social behaviour and hence competence. Such a stereotypical view of children and childhood jeopardises the recognition of children as what they are at any given time during their development, namely persons in their own right (James and Prout 1997, Lee 2001). It also fails to recognise life experiences and their impact on a child's maturity and individual development independent of age.

Further, viewing children through the 'becoming' lens underlines adult authority over children in that it defines adults as 'beings' and thus as competent. It is only a very small step from here to the belief that adults know what is best for children. In this context, Priscilla Alderson's work on children and their consent to surgery is of interest and can serve as example (Alderson 1993, 1994, Alderson and Montgomery 1996). Alderson (1993) interviewed 120 children (age range 8 – 15) who underwent orthopaedic surgery. Research participants represented a group of children who had considerable illness experience due to the chronic nature of their conditions. Some of the children underwent limb lengthening procedures which are painful and lengthy in time since more than one invasive procedure is involved. Yet, her research shows

even young children were able to understand medical information if time was taken to explain it to them. Comprehension of medical information is linked to competence in making a decision for or against an invasive procedure such as limb lengthening, and within a developmental psychological framework this ability is usually assigned to older children or adults. Based on her data Alderson argued that:

‘competence to consent is not a fact, and it does not appear to develop evenly and gradually. Competence has more to do with qualities, experiences and perceptions’ (Alderson 1993:193).

The chronic nature of participants’ conditions are of significance since this links illness experience with children’s perception of their quality of life as they experience it in their everyday lives. It appears that it was for this reason that even children as young as four years of age were perceived by some practitioners as being able to understand proposed treatment procedures. Findings like the above directly question a developmental psychological understanding of children’s general inability to comprehend medical information before a certain age and thus their incompetence to actively participate in their own health care (e.g. Miller 2000, Sartain et al. 2000, Sutcliffe et al. 2004, Alderson et al. 2006). There is however a clear tension between children’s rights to consent to treatment (or to refuse it) and the overriding rights of other adult interest groups, i.e. parents, health care professionals or courts in their attempt to protect a child’s well-being and thus act in ‘their best interest’ (Devereux et al. 1993, Baxter et al. 1998, Foreman 1999, Department of Health 2001, Lee 2005).

The sociology of childhood draws attention to children’s voices in society. Qvortrup (2002) referred to this new interest in childhood and children as a ‘new wave’ within sociology which is underlined by a number of edited books addressing a variety of issues, including those of everyday life experiences, family, school or policies directed towards children (e.g. Mayall 1994, Brannen et al. 2000, Prout 2000, Alanen and Mayall 2001, Hallett and Prout 2003, Hengst and Zeiher 2005). The epistemological stance adopted by childhood sociologists is increasingly, implicitly or explicitly, used within health care research to draw out children’s voices on these matters (e.g. Sartain et al. 2000, Carter 2002a, Stewart 2003, Forsner et al. 2005a, 2005b, Alderson et al. 2006, Kortessluoma and Nikkonen 2006).

In theorizing children and childhood James and colleagues (1998) have developed a model from which childhood and children's lives can be viewed. They assert that their model emerged out of two identifiable research perspectives within the field. While one perspective emphasises children as competent and recognises them as social actors, the other view pays attention to structural issues of childhood that define children's social spaces (James and James 2004). Within these two perspectives there are four further distinctions in reference to children: the tribal child, minority group child, socially structured child and the structural social child.

The child as social actor

The child as social actor can either be understood from a 'tribal' model or as a minority group child. Tribal children are understood to live in their own childhoods that, whilst influenced by the adult world, are nevertheless independent places with their own culture, rules, rituals and normative constraints (James et al. 1998). The focus is on the child as component of a group and thus looking at the relationships children themselves have with others. Corsaro's (2003) ethnography about children's friendships in pre-school is such an example. Corsaro describes nicely the co-construction of a pre-school culture that is actively created by the children themselves through their play and activities according to their rules, rituals and norms.

In contrast, assigning a child to a minority group serves the politicization of childhood (James et al. 1998). Within this perspective a parallel is drawn between the status of women and children and their relative lack of power compared to men within society and hence their social minority group status (e.g. Alanen 1994, Oakley 1994). The focus in this approach is informed by what is common to all children within the social space of childhood (James and James 2004). It is however this way of seeing children as minority group that positions children in opposition to adults and adulthood and therefore manifests power differentials precisely because of the membership in a minority group.

Mayall (2002), for instance, suggests that childhood agency has to be understood within the boundaries of childhood as a minority status. The adults' view of children as 'becoming' and therefore their need of protection and guidance and so on has an

identifiable impact on children's agency precisely because it can only be enacted within these boundaries. The question whether children have rights and if so, what rights and under what circumstances an adult society grants them (Archard 1993, Lee 2005), is an example of power differences between adults and children which in turn impacts on childhood agency. In essence, the political function of this perspective lies in questioning the existing power relationship between adults and children and consequently is an attempt to rebalance power asymmetries between these two groups.

Structural aspects of childhood

Within a structural perspective childhood and children are viewed either as a socially structured child or as a social structural child. The socially structured child is defined as a 'person which is comprised through a series of, often heterogeneous, images, representations, codes and constructs' (Jenks 1996:32) and hence notions of child or childhood emerges as results of discourse. Viewed this way, it is quite obvious why children and childhood are understood differently from the perspective of a parent, teacher or health care professional since different discourses produce different versions of 'the child' or 'childhood'. There are, as Stainton Rogers (2001, 2003) observes, no taken for granted realities out there to be discovered but rather realities that are socially constructed through discourse within a given context. Wyness points out that a radical social constructionism stance, as advocated by Stainton Rogers, completely disembodies childhood and only leaves us with the constructed accounts of childhood with 'nothing beyond or underneath' it (Wyness 2006:18). His interpretation is reinforced by James and colleagues (1998) when they argue that this approach to childhood is hermeneutic in its attempt to question standards of judgement and truth in relation to children. The close link between social constructionism and cultural relativism proposes the variability of children and childhoods in emphasising the absence of an ideal type, and therefore 'is well suited to prise the child free of biological determinism and thus to claim the phenomenon, epistemologically, in the realm of the social' (James et al. 1998:28). In essence, this approach underlines the existence of different social realities which are influenced by one's being within a cultural and social context.

In distinction to the above, a social structural approach views children and childhood as a permanent feature of society. Childhood is understood as a particular structural social form during children's lives that is at the same time independent of the individual child or age (Qvortrup 2002) and so emphasises that children are members of ordinary social life (Alanen 1998). Perhaps logically, childhood is consequently defined to be 'the life-space which our culture limits it to be, i.e. its definition is through the courts, the school, the family, the economy, and also through philosophy and psychology' (Qvortrup 1994:3) but crucially it is a transitional 'life-phase'.

Within a European context, the European childhood project *Childhood as a Social Phenomenon* raised awareness of children and childhood as a lasting element of social structures and hence societies (Qvortrup et al. 1994). On this macro analytical level childhood is seen in its singular form. This is not because there is only one childhood in existence but rather, it is argued, because children live within a defined context of time, space, economic, geographical area and so on and therefore share some overall characteristics (Qvortrup 1994). Hence, the focus remains on children as a structural group within societies as opposed to an individual child's childhood. It is argued by a number of authors that such an approach brings children into view in their own right and thus contributes to their visibility within society (e.g. Qvortrup 1994, 1997, 2002, 2005, Oldman 1994a, Alanen 1998, 2003, Alanen and Mayall 2001, Sgritta 2005). While recognising that children have different competencies compared to adults, it is at the same time implied that children and adults hold equal importance as research subjects (James et al. 1998).

Generation

From a social structural perspective 'generation' emerged as one important variable in childhood studies. In fact, it has been suggested that childhood is a generational phenomenon, defining generation consequently as a key concept in understanding children's lives and their childhoods (Qvortrup 1994, 2002, Alanen 1994, 2001a, 2003, Mayall 2000, 2002, 2003). The term 'generation' is used in childhood studies to emphasise the relational aspects of children. Närvänen and Näsman (2004:72) explain:

‘That is, the meaning of ‘child’ as a social position is understood in relation to the other positions in relation to which it is defined – those of parent and adult. Therefore focus is on the construction of these relationships and how the people in those positions relate to one another, and in their agency towards one another reshape, question, negotiate, and change their own and the other’s position.’

While Qvortrup uses the term ‘generation’ in reference to a permanent social structural form in society and thus on a macro level of analysis, Alanen (1994, 1998, 2001a, 2001b, 2003) and Mayall (2000, 2002, 2003) incorporated Karl Mannheim’s (1952) sociology of generation on a micro level of analysis into childhood studies. In general, the term ‘generation’ is generic and used in everyday discourse, hence has multiple meanings which refers to different phenomena, for instance, family relations, cohorts, a measure of time, historical or social periods and welfare and consequently its use can create confusion (e.g. Pilcher 1994, Attias-Donfut and Arber 2000, Alanen 2001a, Närvänen and Näsman 2004, Hill and Kopp 2004, Alwin and McCammon 2004). In reference to families, the term ‘generation’ is often used as a measure of time in distinguishing different generations e.g. grandparents, parents or children. In relation to childhood sociology, Alanen specifically departs in her discussion of generation from Mannheim’s (1952) sociological standpoint while Mayall appears to adopt Alanen’s standpoint in her work.

MANNHEIM’S CONCEPT OF GENERATION

Karl Mannheim (1952), a German sociologist, linked the processes of the formation of a generation to social change. He defined the term ‘generation’ when he argued that ‘in order to share the same generation location, i.e. in order to be able passively to undergo or actively to use the handicaps and privileges inherent in a generation location, one must be born within the same historical and cultural region’ (Mannheim 1952:303). Generation location, in turn, is based on the biological rhythm of life such as birth and death, a limited life span and aging. He is however careful to clarify that it is a mistake to explain or deduce the sociological phenomenon of generation on these biological factors (Mannheim 1952:290). Instead, an identifying characteristic of a generation is the experience of an event in the same time period during a specific biographical life phase (Pilcher 1994, Corsten 1999, Alwin and McCammon 2004).

For instance, childhoods in a divided Germany differed for children born in the same time period, whilst children born after the Reunification grow up in a united Germany and therefore experience a very different German society.

A generation in the Mannheimian sense, is a group of people who were born at the same historical period in a geographical limited region, sharing related formative experiences which are interpreted and understood in a similar way thus triggering a comparable response to their generational problems. Examples of identified generations are the post-war generation, generation '68 or generation Golf¹ and so on. Equally important, once defined as being a member of a generation, individuals do not move between generations but rather different generations are in constant interaction with each other (Mannheim 1952).

It is this understanding that Alanen (2001a, 2003) takes as a point of departure in her integration of generation into childhood studies. She goes further on to argue that the concept of generation 'becomes an explicit concern when the (historically varying) childhood phenomenon is brought into a structural frame' (Alanen 2003:32) since it is this social structuring, namely the ordering of generations, that distinguishes children as a population group from other groups in society. Referring to a micro level perspective, Porpora (1998) points out that units like families can be understood as systems of relationships, linking men, women and children with each other, while emphasizing at the same time that all positions are social positions. Generation in this sense is not a social structure as is class or gender (Alanen 2003), rather it is interpreted as a 'nexus of connections' that causally affects an individual's actions and is affected by them (Porpora 1998). The causality is manifested through a number of structural interests within families e.g. power, resources, gender or constraints. The family, so Alanen (2001a, 2003) argues, is a case of internal structural relations in that the position of a parent cannot exist without the other, namely that of a child. At the same time the notion of reciprocity or feedback within systems explains why the action

¹ Generation 68 and generation Golf refers to German phenomena. Joschka Fischer, the former foreign minister, for example, belongs to Generation 68. The generation Golf is a reference to people born between 1964 and 1975 and a revival of traditional values thus averting from postmaterial values of former generations. See: Jureit, U. and Wildt, M. (2005) *Generationen - Zur Relevanz eines wissenschaftlichen Grundbegriffs*, Hamburger Edition HIS Verlagsgesellschaft, Hamburg.

of one individual is affecting the action and reaction of another thus emphasizing the interdependence within families' relations. Given the status differences between adults and children, it follows logically that familial generational structures are often characterised by asymmetries.

In focusing on the internal connections in children's relations to their surrounding social world, the social processes of constructing and reconstructing children and childhood, adult and adulthood are brought out (Alanen 2001b, 2003). Construction, so the argument goes, inevitably involves agency (Alanen 2003). An agent is someone who negotiates with others, 'with the effect that the interaction makes a difference – to a relationship or to a decision, to the working set of a social assumption or constraints' (Mayall 2002:21). Children's agency however has to be understood within the boundaries of childhood and hence existing power asymmetries between children and adults (e.g. Mayall 2002, Kuczynski 2003, Lee 2005).

The aim in incorporating generation into childhood studies is 'to detect the range and nature of the agency of living children, the *generational structures* from which children's powers (or lack of them) derive' (Alanen 2003:42, Italics in original). This would establish 'generation' as an explanatory social category, comparable to those of class or gender (e.g. Wyness 2006).

There is however a fundamental problem with how Alanen understands and integrates Mannheim's concept of generation. Mannheim explicitly refers to 'historical or social generations' that share a specific historic event which, in turn, has influenced a generation's vision of the world. Consequently, the problem in using Mannheim's (1952) notion of generation within childhood studies lies in the fact that generations in the Mannheimian sense are determined *a posteriori* (Attias-Donfut and Arber 2000, Närvänen and Näsman 2004). A main effort of the sociology of childhood lies in prising out 'the child of biological determinism' and claiming the phenomenon from a sociological stance (James et al. 1998:28). It is therefore somewhat ironic that it is precisely because of the children's chronological age that they cannot form a generation in the Mannheimian sense. Mannheim (1952) clearly defines 'youth' as the

time period in which a generation may form. Consequently, this particular understanding of generation is misguided within childhood studies.

The term 'generation' is generic and often used in everyday discourse (see above). I concur with Närvänen and Näsman (2004) when they argue that 'generation is a problematic term and should be avoided unless developed theoretically.' This, however, childhood sociologists have so far failed to do. Further, it appears that childhood sociologists working within the realms of generation actually lay emphasis on the relational aspects of the notion of 'child', that is the child as a social position is understood in its relation to other social positions (Närvänen and Näsman 2004). It is the implicit power asymmetry inherent in this notion of generation, in the sociological sense as outlined above, within a relational approach that is useful in understanding children and childhood in its relation to adult and adulthood. Accordingly, it is this conceptualization of children as social actors and thus their agency and their relationality that is of interest in understanding children's experiences of critical illness in their family. Generation only comes into the equation insofar as it refers to a measure of time within families.

The following section defines what constitutes a child, children or childhood and shows that, in fact, children are not a homogeneous group within the sociology of childhood and thus society.

Definition of terms: the child, children and childhood

Terms like child, children and childhood are elusive and their meanings depend on one's own position. Parents, for example, would most likely adopt a developmental model as depicted in the 'human becoming' model discussed in the previous section of this chapter.

In fact, within sociology of childhood 'childhood' itself is subdivided into age categories: early (0-4 years), middle (5-9 years) and late (10-14 years) childhood while the period between fourteen and seventeen is referred to as adolescence (Wyness 2006). However, unless a specific childhood period is the focus, for the most part reference is made to 'childhood'. Ironically, this subdivision of childhood suggests a

‘developmentally’ inspired thinking about different age groups of children within childhood.

On the other hand, the legal perspective in the UK defines a child as being a person under the age of eighteen (Masson 2000, 2004).² In Scotland the situation differs slightly from the rest of the UK. The Children’s (Scotland) Act (SE 1995, section 2.3.5) defines a child as ‘being under the age of 16 years’ but points at the same time towards parents’ responsibilities to provide guidance to their children aged between sixteen and eighteen. The inherent ambiguity in the Scottish definition is problematic. For one, it is somewhat puzzling how a child, on one side of the equation, is legally an adult, while on the other side of the equation, parents are specifically called upon to guide their children till they are eighteen. This in itself is a contradiction. Either one is legally an adult, with all rights and responsibilities, or one is not. It is the notion of a partial legal competence before the age of eighteen that produces problems in health care. The area of consent referred to earlier in this chapter provides one such example.

In this context, the term ‘Gillick-competent’ is of importance. A ‘Gillick-competent’ child is a child that is perceived to ‘have the competence to make a decision in a specific set of circumstances’ (Dimond 1996:55). It can, of course, be argued that this is recognising children’s increasing capability to understand the consequences of their decisions and hence their ability to make decisions affecting their own health. This developmental perspective is the stance the Scottish Children Act puts forward. The crux lies in the courts’ power to overrule a child’s decision, even if the child is deemed ‘Gillick-competent’, should the decision against or for treatment not reflect the view of others, i.e. adult health care professionals and subsequently courts (Dimond 1996:59). Anorexia nervosa is a classic example of such a situation, whereby the law protects not the child’s right to consent or refusal to treatment but the child’s life.

In essence, while a measure such as the ‘Gillick-competence’ does exist hence granting children the right to have their say, ultimately they depend on adult assessment of

² While these are chapters in two different books they are almost identical in text

whether or not a specific child is deemed ‘Gillick- competent’ and of whether the decision a specific child takes is acceptable to adults in health care or the judiciary.

In contrast to the above, James and James provide definitions from a sociological perspective on terms like childhood, the child and children. They propose that:

‘[] childhood’ is the *structural* site that is occupied by ‘children’, as a *collectivity*. And it is within this collective and institutional space of ‘childhood’, as a member of the category ‘children’, that any *individual* ‘child’ comes to exercise his or her unique agency’ (James and James 2004:14, *Italic in original*).

This definition proposes childhood as socially constructed. Historically, it was the French historian Philippe Ariès (1962:128) who stated that ‘in medieval society the idea of childhood did not exist’. While he was criticised for this particular assumption (e.g. Pollock 1983, Archard 1993), his central thesis, namely that the concept of ‘childhood’ is socially constructed and influenced through temporal, spatial and cultural factors has been accepted by many (e.g. Alanen 1994, Jenks 1996, Prout and James 1997, James et al. 1998, Lee 2001, Goldson 1997, 2001, James and James 2004) and is also evident in the above excerpt. According to James and James (2004) the acceptance of this proposition has two main effects for understanding childhood. Firstly, that childhood as such can no longer be regarded as an unproblematic time of growing up but as a time phase within the life course that is influenced by ever changing political and historical factors and secondly, that the perception of adults and their behaviour towards children has an influence on children’s experiences of being a child.

These distinctions are important because a child is an individual and consequently differs from the collective of children. It is equally misleading to refer to ‘the child’ when actually the collective of children is the point of reference (e.g. James and James 2004), as for example, happened in the United Nation’s convention on the rights of the child. ‘The child’ is always socially and historically situated and thus an individual. Consequently, it is the individual child as well as children who are active in constructing and co-constructing their own lives and the lives of others around them

and hence of the society in which they live (see James and Prout 1997:8) that is helpful in illuminating children's experiences during a time of family illness. What is also evident in this argument is that children construct their own childhoods and thus have an impact on how children live their lives. In other words: childhood is a permanent social structure while at the same time it is socially constructed.

Conclusion

'No member of a family is a sufficient source of information for that family'
Gerald Handel

In past decades nursing research within the realm of intensive care has without doubt established family members' needs during critical illness. Over two decades of CCFNI studies have also underlined the difference in perception between families, nurses and physicians of those needs.

The quantitative approach taken in CCFNI studies resulted in excluding children from families since the instrument was never developed for its use with children. Consequently, their needs within this particular research focus were and are not heard.

It is further evident from this literature review that the identification of needs has not lead to interventions with families. This is not surprising given the fact that firstly, elucidating the meaning of identified needs is not within the scope of a quantitative research approach and secondly, nurses' views on families in a critical care setting have been largely overlooked. Yet, nurses' views are of importance since it is the nurse that is most likely to intervene and support families during this time.

A number of qualitative studies draw out the complexity of family members' experiences during critical illness. Though few in number, these studies start to add depth to what identified needs might mean and thus enhance our current understanding of families' experiences in ICU. While this is certainly the case, children are designed out of most studies and consequently their experiences remain largely hidden. The conceptualisation of family across studies is particularly problematic. 'Family' and 'relative' are terms that are often used interchangeably thus making comparison of

research findings difficult. However, 'family' or 'relative' too often translates into a research focus on one family member. Family research in this context is more often not family research but research on a subgroup of a family. That there are differences in perception of a critical illness experience is most notably evident in research including more than one family member (e.g. Titler et al. 1991, Craft et al. 1993). Consequently, I agree with Handel (1996) when he argues that one family member cannot speak for a family.

Further, children are undeniably part of many families. Listening to their experiences is thus paramount in research examining families' experiences with critical illness. Here, the relational approach as advocated by the sociology of childhood is helpful in reintegrating children into their families within a family research context.

In conclusion, it is evident from the literature that there is a lack of qualitative research into the experiences of families in ICU settings. Within this scenario, nurses play a vital role and therefore have to be part of the picture not only in trying to understand families' experiences but also in developing nursing interventions focusing on families.

CHAPTER 3

Methodological Issues

Introduction

The following chapter gives a detailed account of the approach taken to this study, its background, methodological and theoretical position in relation to Grounded Theory General Systems Theory, Cybernetics and research with families and groups are addressed. In relation to the method chosen, data generation, management and analysis procedure are discussed.

The motivation for this study was based on my own observations as a nurse of families in intensive care. Over a number of years I had observed families struggling to make sense of what was happening to them during a critical illness and that our (nurses) almost exclusive focus on the patient resulted too often in failure to support families. The family was an afterthought in nursing. Living and working in Germany the issue of families in intensive care was not raised or discussed in nursing journals or education. This situation left me wondering what experiences families go through during a critical illness.

It was during my Master studies, at the University of Edinburgh, that I came across a study unit entitled *Families in Transition* that suggested a possible way of re-conceptualising nursing care of families. Reading the literature around families, critical illness and family nursing it became evident, as indicated in Chapter 2, that the issue of families in ICU has been predominately approached from a quantitative perspective. While this research led to a good and grounded understanding of individual adult family members' needs, it did not clarify families' experiences. Nor did it shed light on children's experiences with critical illness in their families. In addition, I realised that research on nurses'³ views on families in intensive care units was also missing from the literature. An exception to this was family needs related

³ The nursing focus in this study is intensive care nursing. The shorter term 'nurses' is used in reference to ICU nurses.

research, where the literature suggests that nurses' views on families' needs differ from the views of families. This identified knowledge gap provides the rationale for including nurses in this study. From a practical viewpoint it is nurses who will implement any future family interventions, so their views are obviously significant.

Early in the design stage it appeared that one possible way to approach the study of families was to use one of the many quantitative instruments examining interaction, behaviour or functioning in families and so on. Reviews of a number of instruments suggest that the issue of whole family research has not really been resolved in this area, resulting in instruments and usage that more often than not focus on subgroups within families, i.e. parent-toddler, marital system, parent system, siblings system and so on (Sawin and Harrigan 1995, Kerig and Lindahl 2001). Further, Scott (2000) points towards the difficulties involved in ensuring that survey instruments are sensitive to the wide range of developmental stages during childhood. In addition, there is to my knowledge no instrument available to examine nurses' views on families. Consequently, a quantitative approach was rejected for this research.

The scant qualitative evidence available in the literature hints at the complexity of families' experiences during a time of critical illness. One problem with the available evidence, as argued in Chapter 2, is the source of information: usually based on an individual adult family member rather than multiple voices within families. The impact of critical illness on a family as a unit, which includes the children, has not been the focus of enquiry. For this reason, an inductive research approach in examining the social phenomena of critical illness in families and their experiences in ICU and nurses' views on families within this setting is justified.

The study

The purpose of the study is to advance understanding and gain new knowledge in the care of families in ICU settings, thus eventually contributing to a family-derived theoretical framework in the nursing of families.

The study was designed to gather data from individual families' accounts of their experiences in ICU; gain a deeper understanding of a critical illness event in families

by including the children's perspective and to uncover ICU nurses' perception of families.

The following guiding research questions were formulated to explore families' experiences with critical illness in an ICU environment and nurses' perceptions of families.

- How do families process a critical illness event?
- How do children process a critical illness event within their family?
- How do ICU nurses perceive families within the unit?
- What is, from the nurses' viewpoint, the role of the family within an ICU?

Essentially, the questions are process related questions seeking to tap into the social phenomenon of critical illness from the insider's perspective. It is the specific focus on processes and social relations within families and the group of nurses that further justifies a qualitative approach to this study.

Qualitative research

In nursing, researching issues of health and illness from a qualitative perspective is a relatively recent development. Melia (1997) reminds us that as recently as the end of the 1970s there was little expertise in qualitative research within nursing. More generally, other authors comment further on the rapid development and interest in qualitative research in past decades (Atkinson et al. 2003, Seale et al. 2004) reflected in the large number of qualitative research textbooks available today. The diverse development within this form of inquiry has unfortunately led to 'a good deal of muddle and confusion' (Atkinson et al. 2003:1) in relation to basic issues in qualitative research. Seale and colleagues (2004) agree with this last point and call attention to the danger of abstraction and hypertheorization of qualitative research. They suggest that debates and textbooks on qualitative research should foreground practical activities since this is the route by which students or new researchers learn the trade.

In accepting the argument that contemporary qualitative research is diverse, the absence of an agreed definition of qualitative research (Denzin and Lincoln 2005) seems logical. One understanding refers to 'qualitative' as an umbrella term under which different types of qualitative approaches are described (Guba and Lincoln 1994). Creswell (1998), for example, suggests five qualitative traditions of inquiry: biography, phenomenology, grounded theory, ethnography and case study. These traditions do not share the same disciplinary background but represent a cross-section. Green and Thorogood (2004:5) suggest that 'the most basic way of characterizing qualitative studies is that those aims are generally to seek answers to questions about the 'what', 'how' or 'why' of a phenomenon, rather than questions about 'how many' or 'how much' while Bryman (2004) points out that qualitative research strategies are inductive, constructionist and interpretivist, even if not all qualitative researchers subscribe to all three features.

In sum, the view that qualitative research is pragmatic, interpretative and grounded in the lived experiences of people is well supported in the literature (e.g. Denzin and Lincoln 1994, Mason 1996, Creswell 1998, Marshall and Rossman 1999, Flick 2002, Green and Thorogood 2004, Bryman 2004).

It follows that qualitative research takes place in a natural setting where the researcher is the means of data collection. Data collection is flexible and sensitive to the social context in which data are produced. Data analysis is based on rich, contextual and detailed data with the aim of elucidating meanings people bring to the data through interpretation in order to understand the phenomenon under investigation (e.g. Mason 1996, Creswell 1998, Marshall and Rossman 1999, Denzin and Lincoln 2000, Flick 2002, Kuczynski and Daly 2003). In essence, the research approach chosen must reflect the best fit to answer research questions and thus is guided by them (e.g. Silverman 1997, Flick 2002). Reflecting on my previously stated research question grounded theory was identified as the appropriate methodology to explore families' experiences during critical illness and nurses' views on families in ICU while focus group interviewing was the guiding method employed for both groups.

In the next section I addressed first both groups of interest before turning to the methodology chosen.

Researching groups: families and nurses

The approach taken in this study is one of interviewing groups as opposed to individuals. An advantage of group interviews is that they provide access to interactions between participants and therefore offer insight into how social knowledge is produced (Green and Thorogood 2004). It is exactly this access to the co-construction of meaning, processes and norms within groups (e.g. Carey 1994, Kitzinger 1994, 1995, 1996a, Bloor et al. 2001) that is sought in order to understand the social processes firstly, in families that experience critical illness and secondly, in uncovering nurses' perceptions of families in ICU. Group data differ in comparison to individual interview data in that there needs to be a balance between looking at the individual voices within groups and the picture provided by the group as an entity (e.g. Carey 1995, Morgan 1997, Reed and Payton 1997, Catterall and Maclaran 1997, Kitzinger and Barbour 1999, Kidd and Parshall 2000). In relation to families a systems approach has frequently been adopted in conceptualising 'family' (e.g. Doherty and Campbell 1988, Wright and Leahey 1994, 2000, 2005, Friedemann 1989, 1995, Whyte 1994, 1997a, Bomar 1996, 2004, Boss 2002a, Hartrick-Doane and Varcoe 2005) and is equally fitting to other groups such as nurses (e.g. Forsyth 1999, Arrow et al. 2000).

General systems theory

General Systems Theory (GST) was formulated by Ludwig von Bertalanffy (1950, 1969)⁴ as a response to scientific attempts to explain phenomena by focusing on their interplaying units which resulted in investigating parts independently of each other. According to von Bertalanffy, scientists across disciplines, including physics, chemistry, biology, computer science but also psychology, sociology and philosophy, at the time recognised that the whole is behaving differently than its independent parts but lacked a 'general superstructure of science' which would be applicable to any

⁴ Von Bertalanffy's writings are dated in the 50s and 60s of the last century. After the Second World War he immigrated to Canada where he became later a Professor for Theoretical Biology at the University of Edmonton. He was born in Austria and his earlier systems related writings appeared in German and are thus usually ignored in the Anglo-American literature.

system irrespective of the properties of the system or elements involved in that system (von-Bertalanffy 1950:136-137). As a result, GST evolved around the concept of wholeness. A system in this context is defined as a 'complex of elements standing in interaction' (von-Bertalanffy 1969:33). In essence, GST is a theoretical perspective that 'classifies systems according to the way their parts are organised or interrelated and describes typical patterns of behaviour for the different classes of systems as defined' (Vetere 1987:19) which in effect also leads to a hierarchy of systems. Expressed in a 'logico-mathematical' language, von Bertalanffy argued that his formulation of GST is precisely because of its purely formal formulation, applicable across disciplines (von-Bertalanffy 1969:37). He subsequently identified a number of system characteristics which include openness, wholeness, feedback, boundaries, homeostasis, equifinality and environment (Casey 1996).

Wholeness and feedback

Wholeness refers to the interrelationship of parts to the whole systems, while feedback is the process whereby the parts of the system or subsystems relate, interact and maintain the system's function. The system's ability to control itself is referred to a self-regulation. This ability of self-regulation is evident in physical as well as social systems (e.g. von-Bertalanffy 1969, Turchin 1977, Heylighen 2000, Fuchs and Hofkirchner 2005, Terenzi 2006). The 'feedback loop' describes the circularity of a system's input and output which has an effect on all other system parts. It is this ability to reflect on their own behaviour and thus their explanation and reaction to it, or in other words the self-reflexivity of human systems which is of interest in the context of families (Whitchurch and Constantine 1993). Feedback can either be positive or negative. Positive feedback information changes the way the system functions thus increasing instability. In contrast, negative feedback incorporates information in order to correct the system's response to a stimulus and thus increases the system's stability. In effect, negative feedback functions to maintaining the balance or homeostasis of the system.

Open and closed systems, homeostasis and equifinality

A further distinction is that of open and closed systems. Closed systems are isolated from their environment while open systems are in interaction with their environment

(von-Bertalanffy 1969). Living systems are open systems that maintain themselves through a continuous flow of information in an attempt to maintain a steady state or homeostasis. In this context, the concept of equifinality refers to the system's ability to reach a steady state from different initial conditions and in different ways. In essence, equifinality describes a system's wide-ranging capability to adapt itself.

Boundaries

Boundaries are the concepts that divide systems into subsystems or as parts of larger systems. Boundaries are either closed or permeable. In open systems information and energy flows in and out of the system and thus maintains the system's communication with its environment. The complexity of the system's feedback structure is linked to its ability to monitor its own progress towards a goal and its capacity to change its basic structure or organisation in order to remain viable (Casey 1996). And finally, systems can always be divided into subsystems or be part of a larger supra-system hence creating a hierarchy of systems. In families, for example, there are a number of subsystems (parent-child, siblings, husband-wife and so on) while at the same time, families are part of a wider community, where the community can be viewed as a supra-system.

It is this systems perspective, that the family consists of interacting and interconnected parts and can only be understood as a whole and where parts are interdependent and affect each other that has been widely adopted within family theory (e.g. White and Klein 2002, Bengtson et al. 2005a, Chibucos and Leite 2005). Family theory in turn, serves as a theoretical underpinning within other disciplines such as psychiatry, family medicine, family therapy, family nursing, social work and so on. Viewing the family 'as system' implies that systems, in this context, are not viewed as reality but rather as a metaphor, an epistemological statement that defines a way of knowing (White and Klein 2002).

Other theoretical developments took place in parallel to the advancement of GST (see Heims 1993). The Marcy Conferences, for instance, aimed at developing cybernetics as a meta-discipline (Scott 2001) and this is reflected in the diversity of disciplines from which participants originated (e.g. anthropology, computer engineering,

mathematics, physics, physiology, sociology). The work of Gregory Bateson and his cooperation with Jay Haley, John Weakland and Don Jackson and the Mental Research Institute in Palo Alto, California, links the Marcy conferences and cybernetics to early developments in family therapy.

Interestingly, von Bertalanffy was never a member of this group and in fact disassociated himself from the movement by insisting that systems theory is not cybernetics but rather that cybernetics is part of systems theory (von-Bertalanffy 1969:17). Over time the contributions of both approaches, GST and cybernetics were intermixed and are today often used in this ‘libertine’ way by many when conceptualising families (Broderick 1993). Yet, there are real differences between these two approaches.

Cybernetics

The etymological root of the term ‘cybernetics’ stems from the Greek word *kubernētēs* meaning ‘steersman.’ Norbert Wiener is usually credited for introducing the term ‘cybernetics’ into academia. This is not entirely correct since the term can be traced back to the eighteenth century (Wiener 1954, François 1999, Heylighen and Joslyn 2001). The original contributions to the discipline go well beyond Wiener to include early cyberneticians like Claude Shannon, Warren Weaver, Arturo Rosenblueth or Julian Bigelow amongst others. Heylighen and Joslyn (2001) define cybernetics as the science that studies ‘the abstract principles of organisations in complex systems’, while Wiener (1954) saw it as the study of ‘control and communication in the animal and the machine’.

Within GST and cybernetics living systems are viewed as self-regulating, goal-directed systems that are in constant interaction with their environment through a feedback mechanism (von-Bertalanffy 1950, 1969, Wiener 1954, Smith 1962, Turchin 1977, Terenzi 2006). I suggest that the concept of feedback inherent in both perspectives is the reason why many writers and researchers in family research do not distinguish between these two approaches. There is however a difference between GST and cybernetics that relates to their respective foci. While GST changes the focus from the parts to the whole and is therefore more general, cybernetics changes the

focus from substance to form (Wright and Leahey 2000, Heylighen 2000). In other words, in cybernetics the focus is on how systems use information and control their actions to maintain the viability of the system while at the same time reacting to a variety of disturbances (Heylighen and Joslyn 2001). In addition, the system's ability to adjust future conduct is based on past experiences and performances of the system (e.g. Wiener 1954, Watzlawick et al. 1967, Heylighen and Campbell 1995). It is for the aforementioned reasons, in looking at the inner world of groups – the feedback loop - that cybernetics is of interest to family or group researchers. Watzlawick and colleagues eloquently express this point saying that:

‘[o]ur point is that interpersonal systems – stranger groups, marital couples, families, psychotherapeutic, or even international relationships etc. – may be viewed as feedback loops, since the behavior of each person affects and is affected by the behavior of each other person’ (Watzlawick et al. 1967:31).

In relation to groups second-order cybernetics is of particular interest. In general terms, first-order cybernetics refers to those applications adopting a classical scientific mode, for example, in engineering and computer sciences while second-order cybernetics explores the interaction of social actors (Scott 2001). The second-order cybernetics approach recognises a system as an agent in its own right, which in turn, is interacting with other systems (e.g. observer, researcher) (e.g. Wright and Leahey 2000, Heylighen and Joslyn 2001, Scott 2001). Interaction is viewed as circular and its outcome is influenced by all participating systems, the family or group and the observer. In sum, through the feedback loop behaviour is co-constructed within a system and across systems.

Critique of a systems approach

While a general systems framework is useful for describing time-specific and complex interactional behaviours in groups and families (Vetere 1987) and thus provides an insight into group life, there are also shortcomings of which one needs to be aware.

The notion that ‘the whole is behaving differently than its independent parts’ is recognised within GST in that the system must be understood as a whole and therefore cannot be grasped by examining its parts in isolation from each other (von-Bertalanffy 1969, Whitchurch and Constantine 1993). Over time, this particular assumption has

been associated with the view that ‘the whole is greater than the sum of its parts’ and is frequently mentioned in conceptualising family. In relation to families, Ransom (1983) points out that ‘persons and family constitute and define each other reciprocally and reflectively’ and consequently:

‘it is not that a family is more than the sum of its individuals, but that the individuals themselves are redefined and recreated in the process of their interaction. This recreation, in turn, restructures the family, which creates new conditions engendering further recursive cycles of this kind’ (Ransom 1984:231).

In essence, the variation is related to emerging differences in their behaviour, as individual or as family, and their subsequent reciprocal and reflexive influence on each other. The uncritical adoption of the claim that the ‘whole is greater than the sum of its parts’ is simply wrong in relation to families. That this perception was never based on von Bertalanffy’s understanding of systems is evident when he said that:

‘the meaning of the somewhat mystical expression, ‘the whole is more than the sum of its parts’ is simply that constitutive characteristics are not explainable from the characteristics of isolated parts’ (von-Bertalanffy 1969:55).

Von Bertalanffy (1969) underlines here the ‘constitutive characteristics’ which specifically refer to the relationships between parts as important aspect of the whole, leading to the emergence of new properties of the systems as opposed to parts in their summation. He goes on to say:

[p]hysically, these statements are trivial: they could become problematic and lead to confused conceptions in biology, psychology and sociology only because of a misinterpretation of the mechanistic conception, the tendency being towards resolutions of phenomena into independent elements and causal chains, while interrelations were bypassed (von-Bertalanffy 1969:55).

Therefore, I concur with those authors who argue that the ‘more than’ understanding of systems in relation to families is based on a misinterpretation of GST (Ransom 1984, Feetham 1991, Robinson 1995a, 1995b).

Wellard further points out that systems approaches have been criticised for being ‘de-contextualised from the social world in which they exist and eliminate the conflictual

aspects of social life' (Wellard 1997:79). As a consequence, power relations in systems are implied as equal. This however denies the existence and the impact of power relations that do exist in society, groups and families, for example, related to gender or age (e.g. adult-child) as well as the influence of society on groups such as nurses or families. Neither exists in a vacuum but is embedded in the society of which the family system or the health care system is a part of.

An uncritical adoption of systems theory can also lead to a reinforcement of the idea of system, leading to the perception that the family 'is' a system rather than the abstract view, adopted for this study, that family is viewed 'as' a system (White and Klein 2002). This particular distinction is important since the former relates to an ontological stance while the later refers to an epistemological perspective.

It is equally misplaced to view a living organism, irrespective of whether they are biological in nature or social groups as equal as is suggested by GST. Although, as Broderick (1993) points out, von Bertalanffy defined social systems as 'symbolic systems' which were concerned with meaning and thus represented the highest organisation of systems within his hierarchy, this distinction has often gone amiss in adopting a GST approach. Vetere (1987) makes the point that biological organisms differ substantially from social groups consisting of different individuals. While there are similarities in the sense that both systems maintain themselves, react to stress, reproduce and so on this should not lead to a 'biologism or the reduction of social to biological concepts' (Vetere 1987) in understanding social groups but rather implies that these system principles apply to both areas. Humans possess the ability of self-reflection and therefore can monitor their own behaviour in response to challenges, and this in turn, fundamentally distinguishes human systems from biological systems.

In sum, using a systems approach to conceptualising both groups - nurses and families - allows reflection on the complexity of interaction within and across groups and thus their behaviour and subsequent experiences in relation to critical illness. Further, the underlying constructivist epistemology of systems theory (White and Klein 2002, Dale and Altschuler 2006) allows the researcher to look at families and nurses within their

respective social contexts of ‘family’ and ‘health care system’ in trying to understand the impact they have on each other within systems but also across systems.

In considering the groups of interest the complexity of the study becomes apparent. Viewing both groups as systems in their own right is an epistemological stance that accounts for important differences between families and nurses as groups. In the following section I first consider families as groups before turning to nurses.

Families

‘Defining either families or qualitative research is not for the faint of heart.’
(Gilgun 1992:22)

Gilgun’s quote draws attention to the many different forms of families that can be found in contemporary society and various qualitative approaches available in researching families. As indicated by this quote, areas of concern relate to the definition of family and the research approach taken since both considerably influence the end product of a research undertaking.

What is family?

In reference to families, the insight that ‘families are familiar, but also elusive’ (Wasoff and Dey 2000) is manifested in the fundamental problem that there is no agreed definition of what exactly a family is (e.g. Frude 1991, Copeland and White 1991, Morgan 1996, Anderson and Sabatelli 1999, Greenstein 2001, 2006, Hill and Kopp 2004, Georgas 2006).

Viewed from a cross-cultural perspective, the term ‘family’ is in Western cultures often used synonymously with ‘nuclear family’, defining family as mother, father and their children whilst in other nations around the world ‘family’ often includes grandparents, uncles, aunts, cousins and so on from both sides of the family as well as unrelated individuals who are considered family (Georgas 2006).

In Western cultures, the problem in defining family can be located at the level of language. In search of a family definition Gubrium and Holstein (1990) ask the poignant question what difference the modifier ‘the’ makes? What is the difference between ‘the family’ and ‘family’? ‘The family’ as Bernardes (1997) suggests has

been taken for granted by many in society, including members of political institutions, various religions and academic disciplines. In sociology, for example, the concept of ‘the family’ serves as a baseline, an ideal type of family, to which other family forms can be compared and judged accordingly. ‘Ideal’ in this context is taken for ‘normal’, implying that this is the family form society should strive to create. The problem in defining ‘ideal types’ is that these are theoretical abstractions and do not necessarily correspond with any existing phenomena in the real world (Bernardes 1997). Socio-demographic data show the increasing diversity of family forms in contemporary society while at the same time diversity of families and their living arrangements is more generally accepted by society (McKie et al. 2005). Specifically non-traditional families, such as homosexual families, grandmother headed families, adoptive or foster families, multiracial families and so on (e.g. Okun 1996, Erera 2002) challenge the concept of ‘the family’ in society by bringing out the diversity of contemporary families. In this light, Bernardes’ conclusion that ‘even the roughest analysis suggests that the nuclear family is so rare as to render the whole idea of the nuclear family entirely redundant (Bernardes 1997:10) is, perhaps, not so surprising.

Nevertheless and despite variations in family forms, the family is still viewed as the basic unit of societies. Policy makers, for instance, describe the family ‘at the heart of our society’ (TSO 1998) and thus as a basic unit of care within society. This understanding of family and its function is not accidental but allows policy makers to draw on families and their potential for unpaid work. One example would be the shift from hospital to community care following the Community Care Act 1990, which as Wasoff and Dey (2000) point out deliberately sought to ‘enable’ care provision through family and community. It was this particular shift in care provision that Whyte (1997a) draws on when she suggests the appropriateness of family nursing as a means to support families in their role of caring for often severely ill family members. The notion that family care is gendered and overwhelmingly female is not a new insight (e.g. Finch 1989, Sanborn and Bould 1991, Morgan 1996, McKie et al. 2004). In this context, the need for post-ICU hospital care by the family of former ICU patients is an emerging theme within critical care research, to which Australia has responded by developing the role of the ICU liaison nurse in an effort to support those

families (e.g. Levy 2004, Foster and Chaboyer 2005, Chaboyer et al. 2005, Chaboyer 2006). In England a similar critical care outreach service can be identified (Valentine and Skirton 2006, Durham and Hancock 2006a, 2006b, Hancock and Durham 2007a, 2007b). However, this service focuses exclusively on critically ill patients and their needs for increased care across the acute hospital spectrum.

In accepting the argument that there is no such thing as ‘the family’, research on families needs to be specific in its inclusion or exclusion of various family forms. Rolland suggests that ‘we are advancing past stereotypical definitions of ‘the family’ and the view of normal family life as ‘problem-free’ to recognise that all families are challenged by adversity’ (Rolland 2003:460) thus implicitly underlining contemporary family diversity while suggesting at the same time that illness is a family affair. It is the insight that illness is a family affair that provides the rationale for examining families’ experiences with critical illness from a family unit perspective. Any family that defines itself as a family is included in this study in order to reflect family diversity as it exists in our modern Western society and therefore in families of ICU patients. This follows the family nursing approach discussed in Chapter 2 in conceptualising families as self-defined units that share values, are emotionally connected and willing to support each other.

While my approach to defining family within the study context purposefully denies the importance of biological ties, it has to be recognised that this kind of definition is not always appropriate. Specifically, within the area of genetics where the ‘biology of genetics reinforces the significance of traditional kinship categories, in reaffirming the biological relatedness of kindred’ (Featherstone et al. 2006:6) the opposite is true. Hence, definitions of ‘family’ are context bound.

Researching families

Despite some similarities, there are important differences in researching groups and families. ‘Families are not just some random collection of people, gathering together for a moment’s participation in a research study’ (Copeland and White 1991:4) but groups that share a history and a future and thus represent unique social groups within society (Daly 1992). Families have been conceptualised as interacting and

interdependent groups (Frude 1991) in which family members hold different roles and statuses simultaneously (Greenstein 2001, 2006) and much of their behaviour is private and hidden (Daly 1992, Greenstein 2001, 2006). It is further argued that families share a history, traditions and a future (Daly 1992, Gilgun 1992, Copeland and White 1991, White and Klein 2002), have a built in power hierarchy that is less obvious in other groups (Larzelere and Klein 1987, Copeland and White 1991, Kuczynski 2003) and are intergenerational as well as gendered (Broderick 1993, White and Klein 2002). It is important to recognise that families are not static but dynamic and change in their composition and characteristics over a life-course, for example, through births, deaths, launching of children into their adult life, divorce, remarriage and so on (e.g. Anderson and Sabatelli 1999, Greenstein 2001, 2006). In essence, families can be conceptualised as systems of interrelated individuals that are situated in time, cultural and societal contexts.

Levels of family research

Families are complex social systems and several research design decisions have to be taken when researching families. In relation to data collection, the basic question is whether the research questions can be answered by one family member or a dyad or needs the input of multiple family members in order to shed light on the phenomenon under investigation.

Conceptual levels in relation to family research include the distinction between family-related and family research. Feetham (1991), a nursing scholar, defines family-related research as focusing on individual family members, while family research investigates the family as a unit. Both aspects of research constitute nursing research on families (Feetham 1991). In combination with theoretical assumptions and conceptual frameworks that inform a study design, the distinction between these two approaches is significant since it establishes the unit of analysis for data collection and analysis (Gilliss and Davis 1992). At the same time, Larzelere and Klein (1987) argue that there is 'no single best methodology' to research families, but rather that the optimal methodology reflects the nature of the topic, specific research questions and what is already known in the literature. While Greenstein (2001) supports this view, he also cautions us pointing out that the researcher's preference for a methodological approach

frames the research questions in the first place, and not necessarily the other way round.

In reflection on the identified knowledge gaps in the literature and my research questions, a qualitative approach was deemed most appropriate and thus a study design was required that provided flexibility and supported the inclusion of young people. Further, in drawing on systems theory and symbolic interactionism as underpinning conceptual frameworks, I assumed that no one family member could verbalise the experiences with critical illness for the whole family but that multiple family voices needed to be heard. Consequently, a family unit approach was chosen. The view that it is necessary to include multiple family members in an attempt to provide a greater insight into complex family phenomena is well supported in the literature (e.g. Hess and Handel 1959/1995, Gilliss 1983, Uphold and Strickland 1989, Sullivan and Fawcett 1991, Copeland and White 1991, Daly 1992, McClement and Woodgate 1998, Dale and Altschuler 2006). However, a group approach complicates a research endeavours and Ribbens McCarthy and colleagues (2003) nicely outline the various challenges one faces in including and analysing multiple voices in a study. This issue is addressed later in this chapter.

The advantages of a ‘family as unit’ approach is evident in the seminal work of Hess and Handel (1959/1995). The interplay between family members is eloquently expressed by Handel, who wrote in reference to this work on families, using the ‘whole family methodology,’ that:

‘we conceptualised families as complex active agents in constructing their own family life, and we conceptualise each family member, each child as well as each adult, as an agent whose actions contribute to shaping that family’s interdependent life together – and apart’ (Handel 1996:344).

It is this systems perspective of families that creates space to include diverse family forms, changes over a life-course regarding family composition and characteristics but also pays attention to the duality of family life, namely for the ways that families provide of being a unit as well as separate persons within a family (Hess and Handel 1959/1995), while the research remains firmly focused on processes within families. Consequently, it is this type of data that generates comprehensive family systems data

(Sullivan and Fawcett 1991) necessary to illuminate families' experiences with critical illness.

Family systems data are constructivist in nature and thus do not result in *a* family experience but rather represent the different realities of individuals in groups. It would be a serious logical error to deny that experiences or discussions of meanings in families always represent shared and unshared realities (Broderick 1993). It is the processes by which families share realities, but also maintain and construct their separate realities, within their interdependent and independent lives that are of interest in examining family experiences with critical illness. This epistemological stance is adopted for both groups of interest and provides a rationale for doing group interviews.

Children and young people in family research

Including children and young people in research raises a number of methodological issues. While there are exceptions (e.g. Titler et al. 1991, Snethen and Broome 2001, Hall et al. 2001, Carter 2002a, Dale and Altschuler 2006), there is a paucity of literature on doing research with children as part of their family units. For this reason the majority of literature I draw on focuses on doing research with children as a subgroup of their family. The difference between doing research *on* children and doing it *with* children is emphasised by Carter:

'[i]t is worth noting that for the most part research with families usually means data generated from parents/carers and most often from mothers' (Carter 2005:50).

In Chapter 2 I argued that this is not a unique situation in health care research and reflects the situation in a number of disciplines interested in 'family'. Specifically the above critique, relating to data generation *on* children and their views through adults has been raised by a number of researchers across disciplines (e.g. Ireland and Holloway 1996, Alderson and Montgomery 1996, Hill et al. 1996, Qvortrup 1997, Bricher 1999, Balen et al. 2000/2001, Grover 2004, Irwin and Johnson 2005). While in the past voices of children, healthy or ill seldom featured, there has been a marked shift over the past two decades or so away from seeing children as passive recipients of

adult socialisation towards the recognition that children are agents in their own right (e.g. Hill et al. 1996, James et al. 1998, Christensen and James 2000, Alanen and Mayall 2001, Mayall 2002, Qvortrup 2005, Neill 2005). The introduction of children's rights, the United Nations convention on child rights and the creation of children's commissioners in the UK are examples that indicate a political turn towards children's participation in policy and service design geared towards them. This created a momentum for researchers to include children's voices (e.g. Taylor 2000, Balen et al. 2000/2001, Carter 2005, Irwin and Johnson 2005, Coyne 2006, Kilkelly and Donnelly 2006). This shift towards children's inclusion in research is not only evident in health care but also within sociology and as Hill and colleagues (1996) suggest is reflecting a wider change in adults' attitude towards children in society.

In relation to health care, the inclusion of children in research is mainly manifested within paediatric nursing and focuses on the ill child. Studies including healthy siblings remain the exception (e.g. Snethen and Broome 2001, Van-Riper 2003, Stalker and Connors 2004, Carter 2005). The situation within adult nursing is different again. The literature reviewed in Chapter 2 supports the conclusion that there is a call for nursing the family within critical care. Further, within most family nursing research children as part of the family are currently ignored; instead a dichotomy exists in either focusing on adult family members or on young people. There are exceptions where the research focus remains on the whole family (e.g. Titler et al. 1991, Whyte 1994, Carter 2002a, Coyne 2006) but in the main nursing researchers do not take up the challenge of including families with children as the unit of analysis in their studies. In this context, doing research with children and young people is an area where adult nurses can and should learn from their paediatric counterparts.

There are a number of methodological reasons why nurses might be hesitant to include young people in research. For one, including the whole family in research increases the complexity of a study (Copeland and White 1991, Åstedt-Kurki and Hopi 1996) on methodological, pragmatic and ethical levels (Moriarty and Cotroneo 1993). On a practical level organising and scheduling an interview with all family members is challenging. Different schedules of different family members have to be taken into

account and the researcher needs to demonstrate a great degree of flexibility in timing and location.

Secondly, there are additional ethical issues in including young people, which are closely linked to the 'human becoming' perspective of children and young people as discussed in chapter 2 and hence to children's competence (or perceived lack of it) to consent to participate.

Methodological considerations

Study design is about methodological choices. In relation to this study the chosen methodology needed to support the inclusion of multiple voices within the study design and data analysis. Solberg (1996) suggests that there is no difference between doing research with children or adults and therefore methodological issues do not arise. She recommends 'age ignorance' in approaching research with children. France and colleagues (2000), in contrast, suggest that while developing a method that is grounded in the participant's views does not differ between age groups, this does not mean that methodological requirements in studies including children and young people do not recognise differences between research populations.

Researchers have used a variety of different techniques to elicit children's and young people's voices. Backett and Alexander (1991), for instance, used interviewing and drawing as methods amongst others to elicit children's health related beliefs with children aged between 4 and 12 years. They concluded that drawing helped to establish rapport with children. Coyne (1998) also combined drawing with interviewing 7 to 15 year old hospitalised children. Similar to Backett and Alexander she used drawing with the intention to relax children and ease her way into an interview situation. However, she suggests that drawing can be seen by children as a form of 'test', and thus can have the opposite effect, namely the child withdrawing rather than opening up. Drawing is often perceived by adults as an activity that particularly younger children like to do while it is assumed that older children have outgrown this. Children are individuals in their own right and the evidence in Coyne's study is that while the drawing task was endorsed by some 9 to 13 year olds, other children in the same age range declined. Coyne concludes that:

‘if the child likes to draw then they will react favourably to the request to draw a picture, and the converse of this is that if they do not like or are not skilful at drawing then it will be seen as a chore or a test’ (Coyne 1998:412)

It is evident in the above conclusion that reflecting on sometimes stereotypical adult views of what children like to do at a certain age is important. I considered drawing as one means to ease into the interview with children at the beginning of the design stage but on further examination rejected the idea as too patronising due to the participant’s age range (10 years and above) in this study and the family unit approach chosen.

Integration into the family interview promised to be a more fruitful avenue to follow. The success of interviewing children and young people is partly dependent on their linguistic, social and emotional maturity (Deatrack and Faux 1991, Hill 2005b), while at the same time interviewing as a research technique is not necessarily age specific and even pre-school aged children can be successfully interviewed (Eder and Fingerson 2002). The trick is to ask simple open ended questions, listen and then adapt to the child’s language level and phrase questions in their own words. My motivation to do family group interviews reflects my interest in young people’s perception and interpretation of the critical illness situation in their family and the impact this has on their lives. In specifically including young people I elicit their voices within the context of their family as opposed to suppressing their views in what Oakley (1994) describes as the ideological apparatus of ‘the family’. My view of children in families is based on the assumption that they are social actors in their own right, actively contributing to family life by influencing the way they, as individuals, and their family experience critical illness. In interviewing young people in conjunction with parents, I sought to uncover differences which exist between individual family members and therefore further understanding of families’ experiences during critical illness.

In this context, researchers have to reflect on power issues inherent in research with families. Power dynamics are evident in all interview studies in that the interviewer has control over the research process and asking questions (Eder and Fingerson 2002) and power inequalities between adults and children are evident in research as well as in

families (e.g. Moriarty and Cotroneo 1993, Harden et al. 2000, Mayall 2000, Kuczynski 2003, Hill 2005b). Harden and colleagues (2000) ask the poignant question if children can be interviewed as ‘equals’. They, as I did, came to the conclusion that one cannot change the fact that one is an adult and the respondent a younger person, thus coming to the interview situation with their own knowledge about adults or being a young person. Hence, while this is the context in which an interview is situated a reflexive approach is needed in which researchers critically examine their own role and conduct. In the end, eliminating power imbalances between children and adults might be desirable but whether it is achievable is another matter. In my view, a successful interview is characterised by mutual respect, active listening and inviting children to comment and question, which in turn, creates an interview situation where both, researcher and respondent, form the discourse (Eder and Fingerson 2002). This however, applies to the ethical conduct of researchers in interviewing, irrespective of age.

Ethical considerations

Ethical issues in relation to non-clinical samples, as they are reflected in my study, have received little attention (Hill 2005b). Graue and Walsh’s (1998) stance that ethical behaviour is really about the attitude a researcher brings into the field and interpretation is a good starting point. There are some key principles such as equity, respect for persons, non-discrimination and beneficence that underpin an ethical approach to research (Alderson and Morrow 2004, Hill 2005b). In an actual research context these principles turn into the participant’s rights to information, to consent to or decline participation, to be treated fairly, to privacy and confidentiality and to be protected from harm or discomfort (Hill 2005b). Again, these principles are hallmarks of good ethical research, are not age or group specific and were observed in this study. Issues relating to information, confidentiality and privacy and so on are addressed in chapter 4. In the following section my focus is specifically on ‘consent’ and ‘assent’ relating to young people since it is paramount that participation or non-participation is based on their decision. The literature available to draw on focuses predominately on clinical research with children but identified issues and principles are relevant within my study context.

CONSENT VERSUS ASSENT

In principle, consent can be given either verbally or in writing. Within nursing research, obtaining written consent is considered good practice and thus preferable (Behi 1995). The same argument is made in relation to including children and young people in research (Lindeke et al. 2000) and independent of the form of consent sought (consent or assent) the researcher is required to create information and consent forms for the child participant. The process of writing and evaluating the forms designed for this study is outlined in Appendix 1. It is important to observe that consent is only legally valid if it was given freely and informed.

In Scotland, children obtain the right to consent to treatment at the age of sixteen (Masson 2000, 2004). The law on consent in relation to children below this age is based on the 'Gillick competence' of a child as discussed in Chapter 2 (see also Neill 2005). One way of differentiating legal competency of over and below 16 year old young people has been through the terms of 'consent' and 'assent'.

Consent is a term that expresses an individual's willingness or agreement to something. In relation to non-clinical research, it characterises the competence of an individual to voluntarily consent to participate. The competence to make this decision is based on information made available to the individual that clearly states the risks and potential benefits of the study and what exactly participation requires of the individual. It is part of the consent process that potential participants must have the opportunity to question and clarify issues with the researcher before a final decision is made.

Assent, in contrast, is not a legal term but is frequently used in the context of children who are legally not in a position to consent to research (Broome and Stieglitz 1992). Assent is sought by researchers as an indication that they respect the children's rights to participate in research on a voluntary basis (e.g. Lindeke et al. 2000, Diekema 2003), reflecting the middle ground between independent consent and no involvement in the consent process at all (Lind et al. 2003). However, Joffe (2003) suggests that the term should be abandoned completely. His suggestion is based on the Oxford English Dictionary, which in 1995 defined assent as (1) to express agreement, (2) to consent, and thus is identical with consent as outlined above. In this light, there is no need to

create a special term that confuses and complicates matters further in children's consent to participation. Ethically, the benchmark to inclusion of any child is the voluntary agreement to participate in a study and it is the researcher's responsibility to assure themselves that this is the case.

In conclusion, families are complex social systems and several research design decisions have to be taken when researching families. In relation to methodological choices a decision has to be taken as to whether the stated research questions can be answered by one family member or a dyad or needs the input of multiple family members. In combination with theoretical assumptions and conceptual frameworks that inform a study design, this distinction between a 'family-related' and a 'family research' approach determines the unit of analysis for data collection and analysis (Gilliss and Davis 1992).

The family unit approach chosen for this study allows the inclusion of children and young people and thus draws attention to their experiences with critical illness in the context of their families. I agree with France and colleagues' (2000) position that the basic need to develop a method which is grounded in the participant's views does not differ between age groups but that the method must take account of differences between research populations and hence be adjusted accordingly.

In the same light, ethical issues regarding family research or research including children and young people differ only in the sense that the researcher has the added responsibility to assure themselves that participating young people take part because they want to, ensuring that inherent power asymmetries in relationships between adults and children or families do not infringe on a young person's right to make this decision in his or her own interest.

Families are one group of interest in this research and nurses constitute the other. In the following section I turn to nurses as groups in research.

Intensive care nurses

Intensive care and consequently, intensive care nursing, is a relatively recent speciality within health care whose beginnings can be dated back to the polio epidemic in the

early 1950s (LeFanu 1999, Woodrow 2000). Out of these beginnings critical care developed in countries around the world as an area of expertise. Within the British health care system critical care is separated into high dependency (HDU) and intensive care (ICU). Intensive care is deemed appropriate for patients who require ventilation and/ or support of two or more organ systems, while high dependency care is delivered to patients where a single organ failure has occurred or where patients benefit from closer observations or monitoring of vital signs (Audit Commission 1999b, Scottish Executive 2000). This specific distinction is not made in other European countries nor in North America. This is of interest for two reasons: firstly, the clientele in British ICUs represent the sickest of the critically ill increasing the complexity of care and secondly, comparisons of international studies are compromised because the ICU population differs in illness severity.

At the time of data collection the study unit was classified as a level 3 unit, which means the unit had only intensive care patients. Patients in this unit are usually ventilated and require the presence of a nurse at all times and this is reflected in patient to staff ratio of 1:7. Intensive care nursing evolves around the pathophysiological instability of patients. Nursing knowledge in these areas is complex and includes technological, pathophysiological and psychological knowledge in relation to equipment, patients and their critical illness. The Royal College of Nursing (RCN) guidelines for staffing levels reflect the advanced knowledge base for ICU nurses when they assert that:

‘Staff at the current G grade level must have several years of experience of critical care, an appropriate level of post registration qualification in critical care and an appropriate degree.
Staff at current F and E grades must be able to demonstrate their competence through provision of personal portfolio and hold a formal post registration qualification related to critical care, aiming for degree level education.
All nursing staff should demonstrate personal and professional development by continuous updating of professional and clinical knowledge’ (RCN 2003:9).

The entry level for qualified nurses into intensive care nursing is the D grade level. The skill mix within the health care workforce in ICUs and the complexity of intensive care requires it to be a team effort and nurses and physicians usually have a

close working relationship (Woodrow 2000). Withholding or withdrawing treatment, are examples of this partnership approach where decisions are based on communication and mutual decision making within an intensive care team (Melia 2004).

In essence, ICU nurses represent a highly specialised workforce within the health care system. From a methodological point the question arises as what kinds of group ICU nurses actually form?

What is a group?

‘Group’ as such is a generic term and in its broadest sense might represent nothing more than a collection of individuals (Barker et al. 1995). This meaning of a group is so broad that it is of no consequence since it does not distinguish between random collections of individuals and those who meet for a purpose. Pennington’s (2002) distinction into formal and informal groups is more helpful. Formal groups are characterised by their shared goal, missions and purposes and so on and are typical for organisations. Informal groups, in contrast, reflect the common interests of their members, as for example, in leisure or sport groups.

Following this distinction, nurses are part of a formal work group since they work towards a shared goal (Pennington 2002), namely to provide the best possible care to achieve either a patient’s survival and possible recovery from critical illness or a dignified death. In this context, even small units have a large workforce due to the severity of patients’ illness, their need of constant and close monitoring and the resulting high staff to patient ratio. It is here that formal groups and informal groups intersect since large workgroups are often organised in teams, for example, around tasks or shifts (formal group) while at the same time informal groups form due to common interests or friendships within and across formal groups (Arrow et al. 2000, Pennington 2002).

From a sociological perspective groups can be visualised as interactional networks. Forsyth’s definition, for instance, proposes that ‘a group, then, is two or more independent individuals who influence another through social interaction’ (Forsyth

1999:5). Brown is even more specific in that he proposes that ‘a group exists when two or more people define themselves as members of it and when its existence is recognized by at least one other’ (Brown 2000:3). Both definitions explicitly include the dyad as a group form. The dyad however is a special case since this is the only group that ceases to exist when one member leaves the group. ‘Other’ in Brown’s definition refers to individuals or other groups that are outside the group of interest. This is of importance insofar as it implicitly underlines a shared interest of group members which is recognised by ‘others’, for example families, as a characteristic of this group.

Regarding nurses, Lofland and Lofland’s (1995) define a group as:

‘[] people who interact with some regularity over an extended period of time and who conceive of themselves as a social entity (a ‘we’) form a social group. Informal leisure and work groups, cliques, networks, and families are prime examples’ (1995:107)

This definition is useful since it addresses formal and informal aspects of nurses’ group reality in health care and at the same time explicitly distinguishes nurses from other groups, i.e. families within that setting. This definition also draws attention to the interactional and relational aspects of group life and thus is fitting for conceptualising nurses as a group. Nurses fulfil two basic formal roles: firstly, the role ascribed to nurses by society as caring professionals and secondly, roles that are linked to the individual nurse’s standing within the health care setting (e.g. charge nurse, staff nurses and so on) (e.g. Lofland and Lofland 1995, Pennington 2002).

In sum, nurses are part of a formal work group that is task orientated but at the same time they belong to informal groups within and across that formal group which stand in interaction to each other.

Researching nurses

One of the main differences between nurses and families as groups is the homogeneity of the former and heterogeneity of the latter in relation to age. Workforce groups are homogeneous in the sense that they consists of adults, they are also heterogeneous given the breadth of experiences within these groups. Naturally, individuals hold

different roles reflecting their standing in the organisation which are linked to status and power. Pennington (2002) links roles to sets of behaviours that individuals holding a specific position in an organisation (e.g. charge nurse, staff nurse) are expected to perform. The concept of role is of importance since the scope of practice is associated with different roles in a health care team. In other words, roles function firstly, to allow a distribution of labour, secondly, to contribute to the stability of groups since everyone knows their own role and thus what to do and the role of other team members, and thirdly, roles provide a sense of identity (Pennington 2002). Consequently, roles are closely linked to power and status of an individual and therefore methodologically of interest in a group interview situation where the aim is to elicit variations of perspectives in a team. Further, workforce groups are not static but evolve over time in adaptation to the comings and goings of members and changes in health care policy. The above issues influence a number of methodological choices in researching groups and are addressed in the next section.

Levels of group research

The same general arguments made for the different levels of family research are valid in relation to nurses since these apply to researching groups rather than to specific groups. Consequently, viewing nurses as interdependent parts of a group and drawing on symbolic interactionism I assumed that the experiences, actions, interactions and outcomes of one person are linked to those of other group members (Brown 2000) and thus influence nursing practice. This assumption is theoretically based on a systems view and practically on my own experiences as a nurse. Chesla and Stannard (1997) studied the breakdown of family care in ICU and their findings support the view that the nursing culture of a unit, which is a result of interactions between nurses and health care policies, influences the quality of family care in ICU. Hence, it was vital to listen to multiple voices in group discussions to try to understand how nurses construct their understanding of families in ICU.

Reflexivity in qualitative research

Reflexivity is an essential activity within qualitative research that permeates every aspect of the research process (Hertz 1997, Atkinson et al. 2003, Green and Thorogood 2004).

It recognises that the researcher is part of the process of producing data as well as assigning meaning to those data. Authorship is neither silent nor unimportant (e.g. Becker 1967, Charmaz and Mitchell 1996). It needs to be acknowledged in order to establish trust in one's findings and is eloquently argued by Daly saying that:

[w]henever we are carrying out interviews or are involved in observations, we are socially situated. In keeping with the principles of symbolic interactionist identity theory, who we are and how we are seen in this situation is a product of the interplay between our own motives and the attributions that are made about us under the changing conditions of the situation. Therefore, in any research situation, we present ourselves in a way we wish to be seen, and at the same time are attentive to the way others are seeing us in that situation (Daly 2007: 190).

In other words, how I perceive myself and how I am perceived by others matters since it has an impact on my ability to form relationships with those I wish to study. In this context, Reinharz (1997) draws attention to the various aspects of 'selves' in a research situation:

- Research-based selves: for example, in my own case, being a mature PhD student, being a nurse not attached to the unit, being a listener, being a nurse with ICU experience.
- Brought selves: being a mother, being a member of a family, being female, being German, being a nurse for over 20 year and with experiences in teaching, management and ICU nursing.
- Situationally created selves: being an outsider, being a nurse with ICU experience, being a listener, being a researcher.

Within a research situation there is a degree of fluidity between these selves, allowing for the interactive co-construction between the researcher and the researched of 'who we are' within a given research setting. It is through the reflexive process that we become aware and manage these different identities in a research setting. While I, for example, saw myself as a researcher in the field, others at times addressed different aspects of my 'self' (see Chapter 4).

In relation to families, my ability to listen and my being interested in the experiences of families encouraged families to participate. This view is supported by the number of families who agreed to participate in the study after our initial face-to-face contact. Whilst families knew that I was a nurse with relevant ICU experience working on my doctoral thesis, I did not emphasise my teaching or management qualifications or experiences. I considered these aspects of my professional self simply not relevant in the context of the study. The fact that I was a PhD student underlined my position as an outsider to the unit and therefore I was perceived by families as someone who had the time to listen to their stories. Over time however I realised that most families had their own motivation to participate in this study. These motivations included:

- Self-interest: in those cases where a participant wanted to draw my attention to an issue of their concern or where I was seen as an outsider to the family but with relevant nursing experience who was in a position to verify what they had said to their children.
- Source of information: in those cases where the interview was used by a parent to understand what their children had understood about the critical illness situation but also by some young people to get information about the situation beyond what they had been told by their parents.
- Wanting to help the researcher: this was the motivation of families who were open to research and wanted to help my research by contributing to it.

Nurses, in contrast, related to me within a 'colleague format' in the sense that conversations used a clinical vocabulary which is characteristic of interactions between health care professionals. This, implicitly or explicitly, allowed nurses to form an opinion on my ICU experiences or knowledge. At the same time I was keenly aware that I was an outsider. For example, I took great care in observing the unit rules when accessing the unit. Like any other visitor, I rang the bell for attention and waited to be asked in before entering the actual ICU. In observing the unit rules my intention was to communicate to ICU nurses that I understood and respected that the ICU was their 'turf'. Demonstrating respect for the social space one is to enter also creates space for

the development of a mutually respectful relationship which in turn has a positive effect on accessing the field. Nurses did know about my teaching and management qualifications but again I did not emphasise these aspects since the study's focus was elsewhere. It is, however, true that my management experience enhanced my understanding of workforce issues and the organisation of health care - in particular the multi-professional complexity of intensive care and its impact on nursing care.

The next section considers the chosen research approach of grounded theory.

Grounded Theory

Contemporary Grounded Theory has its roots in the work of the sociologists Barney Glaser and Anselm Strauss. Their original research on the process of dying in American hospitals (Glaser and Strauss 1965) resulted in the now classic book *The Discovery of Grounded Theory* (Glaser and Strauss 1967), which described in detail the methods used in their initial research.

Grounded Theory (GT) is a general methodology for developing theory that is grounded in data which have been systematically gathered and analysed using the constant comparative method (Glaser 1978, Strauss and Corbin 1994). The development of GT evolved as a response by Glaser and Strauss during the 1960s to advances in quantitative research methods which dominated American university departments, journals and funding agencies (e.g. Stern and Covan 2001, McCann and Clark 2003b, Charmaz 2006). In their somewhat cynical critique on the way sociologists were trained to use structuralist and functionalist methods in order to verify theory rather than question or develop it, they proposed an inductive method that supported the 'discovery of theory from data systematically obtained from social research' (Glaser and Strauss 1967:2). In doing so, they challenged the assumption that qualitative methods cannot generate theory and argued for qualitative research as a methodological approach in its own right. Hence, the objective of GT is to develop middle range theory grounded in data (Charmaz 2000, McCann and Clark 2003a).

Evolution of Grounded Theory

The Discovery of Grounded Theory (Glaser and Strauss 1967) was published four decades ago and, similar to qualitative research in general, the method has undergone continuous development. In fact, what a Grounded Theory is and should be is currently somewhat contested (Charmaz 2000, Locke 2001). This situation arose partly as a result of the disagreement between the two founders, Glaser and Strauss, who each took the development of GT from its origin in contrasting directions (Dey 1999, Charmaz 2000) and partly because some authors such as Charmaz (2006) followed the originators' invitation to use their strategies in a flexible and creative way (Glaser and Strauss 1967). That Glaser and Strauss had two different *modus operandi* was known to their students (Stern 1994) but the rift became publicly evident after the publication of *Basics of Qualitative Research* by Strauss and Corbin and is well documented (e.g. Glaser 1992, Stern 1994, Dey 1999, Charmaz 2000). At the centre of the argument Glaser accused Strauss and Corbin of having developed a new method, namely that of a 'full conceptual description' (Glaser 1992:3). Melia's (1996) analysis of the dispute raises the important and reflective question of the usefulness of considering oneself as a Straussian or Glaserian grounded theorist, as Stern (1994) labelled these two different *modus operandi*, and thus continuing in the footsteps of one or the other rather than taking up the original challenge and using the strategies in a flexible way (Glaser and Strauss 1967). A very similar line of thinking is evident in Atkinson and colleagues' (2003) comments. They argue that the original version was driven by the question where does theory actually come from, resulting in the guiding notion of abduction as a mechanism to generate theory. Abduction is the process whereby theory is developed in drawing on the concepts and meaning utilized by social actors including the activities in which they engage (Blaikie 1993). Strauss' departure from this stance in his subsequent writings resulted in a 'convergent procedural orthodoxy' (Atkinson et al. 2003) that considerably undermines the flexibility of its original version.

The implications of the seemingly divergent paths GT has travelled over past decades are reflected in differences concerning its ontological and epistemological underpinning.

Grounding Grounded Theory

Denzin and Lincoln (1994, 2005) describe five moments in the evolution of qualitative research: a traditional period, a modernist period, blurred genres, a crisis of representation and the fifth moment which constitutes the present. Within this scheme they position the original GT firmly within the modernist period which corresponds to a realist stance. Realist ontology assumes the existence of an objective external reality that can be observed by a neutral observer (Locke 2001). It is within this paradigm that Glaser (1978, 1992) positions his subsequent approach to GT. Strauss and Corbin's (1994) standpoint in contrast, assumes an objective reality but also gives voice to respondents and thus moves into post positivism (Charmaz 2000). Their position is a mixture between constructivist notions of GT in acknowledging the voices of respondents and an objectivist's stance in emphasising that the systematic steps in their methodology enable an unbiased data collection. Charmaz (1990) pinpoints the tension of 'being simultaneously subjectivists and scientific' and develops in response a constructivist approach to GT (Charmaz 1990, 2000, 2002, 2006). She argues that:

'By adopting a constructivist grounded theory approach, the researcher can move grounded theory methods further into the realm of interpretive social science consistent with a Blumerian (1969) emphasis on meaning, without assuming the existence of a unidimensional external reality' (Charmaz 2000:521-522).

By adopting a constructivist stance some of the criticisms of modernist GT can be addressed (Bryant 2003). Constructivist approaches in general draw on interaction between participants and researcher, and therefore position the researcher firmly in the research process. This is underlined by Charmaz (2006) who argues that theory depends on the researcher's interpretation and thus cannot stand outside it. It is this constructivist position, namely acknowledging that the dialogue between participants and researcher influences the end product that is fundamentally different to the approaches to GT discussed previously.

Within a constructivist approach the researcher 'constructs an image of *a* reality, not *the* reality – that is, objective, true, and external' (Charmaz 2000:523) in an attempt to understand the complex world of lived experiences from the emic point of view, to grasp an actor's interpretation of a situation (Schwandt 1994). Inherent in this position

is the assumption of multiple realities and thus differences in interpretations. Drawing on these assumptions Charmaz argues that her approach remains rooted in realism ‘because it addresses human *realities* and assumes the existence of real worlds’ (Charmaz 2000:523, *Italic in original*). It is here where the link between symbolic interactionism and GT becomes evident as social reality is constructed over time through shared experiences and communications and then is taken for ‘reality’ (e.g. Locke 2001). In this sense, this type of GT is constructivist in its epistemological orientation since it focuses exclusively on ‘meaning-making activity of the individual mind’ (Crotty 1998:58) and therefore ‘suggests a direction along which to look’ (Schwandt 1994:118). As a result guidelines for conducting a constructivist GT are flexible and methods are used as a means rather than an end in themselves (Charmaz 2002, 2006). It is this flexibility that has been lost in the development of GT in the subsequent writings of its original authors (Atkinson et al. 2003, Bryant 2003).

In search of the ‘right’ grounded theory methodology the shifting epistemological positions that come with the evolution of a methodology have been intensely debated (e.g. Charmaz 1990, 2000, Annells 1996, Wilson and Hutchinson 1996, Dey 1999). Not surprisingly, Dey comes to the conclusion that ‘there is no such thing as ‘grounded theory’ if we mean by that a single, unified methodology, tightly defined and clearly specified’ (Dey 2004:80). It follows that the epistemological underpinning of GT can take a number of theoretical positions, including an interpretive stance.

Despite variations in epistemological orientations, there are a number of key features that can be found in all grounded theories. These relate to:

- Simultaneous collection and analysis of data
- Tracking emergent themes through early data analysis
- Discovery of basic social processes
- Inductive construction of abstract categories that explain and synthesize these processes

- Sampling to refine the categories through comparative processes
- Integration of categories into a theoretical framework

(Charmaz 2002:677).

A constructivist approach was adopted for this study and the following section outlines the application of general GT features in the context of this study.

Using Grounded Theory

It is evident from the preceding discussion that GT methods consist of systematic, yet flexible guidelines for collecting and analysing qualitative data in order to construct theories ‘grounded’ in the data themselves (Charmaz 2006:2). Each GT approach has its own underlying epistemological and theoretical perspectives.

Epistemology

Epistemology refers to the theory of knowledge that is embedded in the theoretical perspective and thus the methodology adopted for a study. Epistemology deals with what kinds of knowledge are possible or how we know what we know (Crotty 1998).

Constructivism is the epistemological standpoint underlying this study. Constructivism assumes multiple social realities that are constructed by human beings and considers the implications of those constructions for their lives and interactions with others (Quinn-Patton 2002). Crotty summarises the position as follows:

‘[i]t is the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context’ (Crotty 1998:42).

It follows, that knowledge and meaning are constructed by social actors as they interact, engage and interpret the world they live in. It is essential to recognise that meaning is not fixed but changes over time through interactions and reinterpretations.

Theoretical perspective

A theoretical perspective indicates a complex of assumptions underlying a methodology, positioning it within an philosophical stance (Crotty 1998:66).

Interpretivism as a theoretical perspective has been adopted for this study. Interpretivism is linked to the concept of *Verstehen* (understanding) and Max Weber, a German sociologist, is often credited with elevating its importance (Schwandt 2000). In order to distinguish between natural and social sciences, Weber argued that the natural sciences focus on causality or *Erklären* (explaining) while the social sciences focus on *Verstehen* (understanding) of social phenomena through interpretation. Both Crotty (1998) and Schwandt (2000) provided philosophical discussions of this difference in the social and natural sciences. Symbolic interactionism is the strand of Interpretivism that has been adopted for this study.

Symbolic interactionism

Symbolic interactionism (SI) is intrinsically linked to GT (Stern 1994, Anells 1996) and is therefore usually the position taken in studies using GT. Milliken and Schreiber (2001) reflected on this link which was questioned by Glaser (1999) but came to the conclusion that SI is embedded in different technical procedures of GT and therefore symbolic interactionism is inherent in Grounded Theory. Charmaz (2000, 2002) supports this view in the sense that she argues the importance of meaning and emergence in SI complements GT.

Symbolic interactionism is usually traced back to the work of George Herbert Mead in the 1930s and his student Herbert Blumer who built on Mead's work (Charon 2001). It was Blumer (1969) who actually coined the term 'symbolic interactionism.' The rich and complex history of SI as an approach is apparent in the recent *Handbook of Symbolic Interactionism* (Reynolds and Herman-Kinney 2003). In fact, it is evident from the *Handbook* that there exist several approaches to SI of which the two major ones are the Iowa and Chicago schools of thought. Layder (2006) points out that both schools centre their attention on the issue of the nature of the self and interaction, but the Iowa school does so in the context of traditional scientific analysis, hence it is associated with positivism. Manfred Kuhn had a major influence on the Iowa version of SI (Benzies and Allen 2001). The Chicago school, to which Blumer and also Strauss and Becker belonged, endorsed a more humanistic approach, attempting to get insider accounts of what is it like to be a member of a group of interest (Layder 2006). It is this form of SI that I draw on in this study.

Blumer (1969:2) states three basic premises that underline SI:

- Human beings act towards things on the basis of the meaning that the things have for them.
- The meaning of things is derived from, or arises out of, the social interaction that one has with one's fellows.
- These meanings are handled in, and modified through, an interpretative process by the person in dealing with things he encounters.

These premises emphasise the fact that human beings are able to think, modify and alter meanings and symbols that they use in action and interaction as a result of their interpretations. Symbols in this sense can be concrete objects but also abstract concepts, ideas and so on. An underlying assumption of SI holds that 'human group life or society exists in action and must be seen in terms of action' (Blumer 1969:6). In essence, social reality is constructed over time through shared experiences and communications and is then taken for 'reality' (Locke 2001). Hence, to understand the meaning families assign to their critical illness experience and thus the implications on their lives, and nurses' perception of families in ICU, interactions between people must be explored.

Principles and practices in Grounded Theory

Despite a variety of detailed guidelines outlining the use of GT, conducting a GT study is 'learning by doing' and hence process learning (Schreiber 2001). Doing GT, in this context, either involves following set guidelines (e.g. Glaser 1978, 1998, Strauss and Corbin 1998) or viewing GT methods as principles and practices that are used in generating the end product (Charmaz 2006). It is the latter position that was adopted for this study and notwithstanding the fact that strategies in the following section are addressed in a linear fashion in reality these are cyclical and interdependent processes.

Sensitising concepts

Sensitising concepts identify prior held ideas or understandings about the phenomenon under study. Having read the literature around families, intensive care nursing and

critical illness and being a nurse with relevant nursing experience in this area I was not a naïve interviewer exploring an unknown aspect of nursing. There is, as Dey argues, a ‘difference between an open mind and empty head’ (Dey 1993:63). Consequently, being aware and reflecting on one’s assumptions allows the researcher to ask particular kinds of questions about the phenomenon of interest (Charmaz 2006). I concur with the view that sensitising concepts provide a starting and not an end point in the journey (Dey 1993, Charmaz 2006).

Theoretical sensitivity

Theoretical sensitivity is described as the researcher’s ability ‘to think inductively and move from the particular to the general or abstract, that is to build theory from observations of specifics’ (Schreiber 2001:60). Again, the development of theoretical sensitivity is dependent on an open mind in asking ‘what is going on here?’ It is this sensitivity to data that allows the analysis and recording of events and incidences grounded in data (Glaser 1978). In this context, writing memos is a helpful technique for reflecting on emerging themes whilst contrasting them to background knowledge in an attempt to guard against researcher induced bias on the data (Schreiber 2001).

Theoretical sampling

Theoretical sampling is a process rather than a step within GT. Theoretical sampling is described as being the:

process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what kind of data to collect next and where to find them, in order to develop his theory as it emerges. This process of data collection is *controlled* by the emerging theory, whether substantive or formal (Glaser and Strauss 1967:45, *Italic in original*).

Hence, theoretical sampling relates to the simultaneous collection and analysis of data. Sampling at the beginning of a study is general and open and becomes focused as the theory develops. This form of sampling functions as a self-correcting step (Charmaz 2002) in that through coding, comparative analysis and memo writing gaps in the data are identified and thus sampling can be directed to fill in these gaps. Charmaz (1990, 2000) recommends theoretical sampling at a later stage so that key themes have

emerged without being forced. It is this procedure that provides GT with its analytical power and grounds the theory in its data.

Successful theoretical sampling is initially based on open coding, that is codes emerge from data through questioning the data about what is happening. Open coding allows the analyst to identify a tentative direction in which a study is developing and areas to find new data before a more specific focus is pursued (Glaser 1978).

This particular form of sampling has consequences for doing GT in that data collection and analysis is influenced by developing categories and therefore neither numbers nor timing of data collection, and sometimes locality, can be predetermined as is the case in other research methods. In fact, the sampling process is entirely controlled by the emerging theory (Glaser and Strauss 1967).

In addition, interview guides are not fixed but change throughout data gathering in response to the emerging theory. Some general questions might be asked to all participants, while through the course of the research specific questions emerge reflecting the developing theoretical focus of a study (Schreiber 2001). This technique is reflected in interview topic guides for this study. The probing and testing of ideas of emerging themes in subsequent interviews were based on previously gained insights, allowing the researcher to either fill gaps in data or discard codes altogether.

In essence, theoretical sampling is the link between data collection and the emerging theory through developing codes and categories.

Data collection

Data collection in GT is one aspect that is not clearly detailed in the literature. While Glaser (1998) asserts that GT is a method that can be used with any kind of data (qualitative and quantitative), Charmaz (2000) points out that GT has become synonymous with interview studies. What type of data are best for the development of GT is somewhat contested (Morse 2001). This is reflected in the diversity of data collection methods used, including observations, interviewing, videos, questionnaires or gathering information in records and reports (e.g. Glaser and Strauss 1967, Locke 2001, McCann and Clark 2003c). What is important in this context is the depth and

richness of gathered data. The mission is to collect sufficient data that fit the task (Charmaz 2006) rather than following prescriptive guidelines.

Given the sensitivity of a critical illness situation in a family and the inductive approach chosen, interviewing was considered the most appropriate form of data collection. This way, families and nurses were in control to either consent or refuse participation in what was clearly a distressing time. In addition and importantly,

[u]nstructured retrospective interviews, in which participants tell their stories about some event from beginning to end, are a natural foundation on which researchers may identify processes. As participants volunteer their stories, these stories provide data that incrementally build the processes and strategies needed to derive grounded theory (Morse 2001:7)

Consequently, interviewing fits the task at hand. I also recognise that in the case of nurses, participant observation within the ICU would have been useful. My decision to refrain from doing so was influenced by the awareness that this would have intruded on families' privacy during a time of great anxiety. Moreover this would have produced a different kind of data relating to individuals rather than groups, creating additional challenges in an already complex research situation. My approach to group interviewing is addressed later in this chapter.

Analysis of data

The principle approach to data analysis in GT is the constant comparative method (McCann and Clark 2003a) where data collection and coding takes place simultaneously. This aspect of GT has four identifiable stages:

- Comparing incidents applicable to each category
- Integrating categories and their properties
- Delimiting the theory
- Writing the theory (Glaser and Strauss 1967:105)

Data analysis is a recursive rather than a linear process. Coding is the tool through which data are conceptualised, identifying patterns and processes evident in the data.

Coding and categorising data

Coding is a process whereby the analyst gets ‘off the empirical level by fracturing the data, then conceptually regrouping it into codes that then become the theory which explains what is happening in the data’ (Glaser 1978:55). Differences in coding however exist between GT approaches. While Glaser (1978) and Charmaz (2000) identify a two step process, namely substantive and theoretical or initial and focused codes, Strauss and Corbin (1998) favour a three step coding schema consisting of open, axial and selective codes.

Open or substantive coding is the initial step of analysis where data are coded in as many categories as possible (Glaser 1978). The unit of analysis from which codes are derived can vary from word by word to line by line or incident to incident (Charmaz 2006) and is dependent on the nature of the data, for example, individual versus group interview data. Most interview studies refer to individual interview data and the generalised recommendation is a line by line coding (Glaser 1978, Morse 1994, Strauss and Corbin 1998, Charmaz 2000) arguing that ‘line-by-line coding sharpens our use of sensitizing concepts’ (Charmaz 2000:515). There are two types of codes: *in vivo* and socially constructed codes. *In vivo* codes are verbatim codes, reflecting participants’ language use, while socially constructed codes refer to codes constructed by the researcher (e.g. Glaser and Strauss 1967).

In relation to group data I argue that coding needs to take account of the ‘snapshot’ as well as the ‘moving picture’ (Catterall and Maclaran 1997) and needs to reflect the interaction and individual actors within codes. The general approach to coding was guided by an incident by incident approach but coding also included single words or lines where appropriate when these data raised analytical ideas in relation to emerging categories.

Whilst coding, the analyst questions the data in terms of ‘what is happening here?’ or ‘what is this incident about?’ or ‘what is this category about?’ and so on and thus is

supporting theoretical sampling and hence refining the focus of the ongoing study. It is this technique that keeps the analyst theoretically sensitive (Glaser 1978). In addition, the constant comparative method forces the researcher to re-examine previously coded data in the light of emerging themes which are then followed up in future interviews.

Open codes do not account for all the data (Glaser 1978). The next phase in coding is therefore theoretical or focused coding. Theoretical codes are emerging codes that ‘weave the fractured story back together again’ (Glaser 1978:72) in searching for relevant links between substantive codes. These codes are more abstract and selective in merging open codes into categories or higher level concepts explaining large segments of data. The goal of this step is the increasing abstraction of analysis through the generation of ‘an emerging set of categories and their properties which fit, work and are relevant for integrating into a theory’ (Glaser 1978:56). Categories are conceptually defined and are bounded by their content and extent, for example, in subsuming several codes into a category that identifies and explains a process or pattern. Open codes which do not fit into emerging categories slip into the background at this stage since they lack analytical importance (Charmaz 1990). As I discussed earlier, coding is not a linear process. Data generated in later interviews might require the researcher to re-examine earlier data and codes anew because a topic emerged that was too implicit in earlier data and thus was ignored but gained importance in later interviews (Charmaz 2006) and thus needs integration into the emerging theory.

Eventually, the analytic process of constant comparison and continuing questioning of the data leads to the identification of a core or overarching category which explains and establishes links between categories and categories to codes.

Memo writing

Memo writing is an integral part of GT and starts immediately with coding. Charmaz describes memo writing as ‘the pivotal intermediate step between data collection and writing drafts of papers’ (Charmaz 2006:72), while Glaser is even more assertive in arguing that ‘memos are the theoretical write-up of ideas about codes and their relationships as they strike the analyst while coding’ (Glaser 1978:83). Memos ‘catch

your thoughts' (Charmaz 2006) and help the researcher reflect on processes and actions identified in the data, clarifying the links and comparisons one makes. Memos thus advance first, the development of categories and later, core or overarching categories. Memo writing helps to link our analytical interpretations with empirical reality (Charmaz 2000), therefore memos become building blocks of the first draft of a theory because they function to conceptually fill out categories and define linkages between them. Diagramming is one form of memo that has been used in addition to more conventional memos in this study. Diagramming can be, and was, used to sketch out the emerging theory (Schreiber 2001). Diagrams can help identify what is still missing from the data, conceptualising the emerging theory and hierarchies between codes and categories as well as linkages between categories.

The core category

The goal of grounded theory is to generate a theory that accounts for a pattern of behaviour which is relevant and problematic for those involved (Glaser 1978:93).

Glaser (1978) immediately clarifies this statement in arguing that the generation of theory evolves around a core category. The core category represents a selected central or core phenomenon that accounts for most of the data in bringing previously developed categories together into a coherent whole (Dey 2004). It looks for the 'main theme' from the participant's perspective. The core category accounts for most of the variation of data, consequently other categories and their properties relate to it. From Glaser's perspective the core category is so important that the failure to identify one results in a GT drifting in 'relevancy and workability' (Glaser 1978:93). At the same time, and in contradistinction to his earlier statement, Glaser (1978) admits that it is possible to identify more than one core category, forcing the researcher to choose one of those identified. Given his emphasis on emergence through data analysis and his belief that a core category will present itself this position seems strangely at odds with the 'emergence dictum'. Further, it leaves the process of identifying a core category unclear.

Charmaz's (1990, 2000, 2006) position, namely that researchers actively create the story line, which does not simply emerge from the data but is grounded in them, is

more plausible. Within a constructivist approach, the core category is developed through a dialogue between researcher and data. Hence, constructivist grounded theorists acknowledge their input and the fact that they define what is happening in the data (Charmaz 2002). In fact, adopting a constructivist standpoint implicitly draws attention to the tension between the processes of interviewing and co-producing data which Daly (2007) describes as being a continuum on which researchers position themselves at different points during an interview. While ‘the goal of interpretive constructionist research is to find out how the conversational partners understand what they have seen, heard, or experienced’ (Rubin and Rubin 2005: 37), the interpretation of these data nevertheless reflects the researcher’s version of their understanding (Melia 1997). Following this line of thinking, constructivists do not claim to have discovered the one real meaning but merely an interpretation of one’s own understanding and participants’ representation of theirs. While this position can be criticized from an objectivist standpoint, it does make the identification of a core theme explicit, including the potential for alternative explanations.

Dey (1999) points in a similar direction when questioning whether a core category is really indicated by the data or if its identification is more the result of a heuristic requirement in order to delimit the theory and thus the choice of the researcher. The delimitation of the evolving theory is then one function of a core category (Glaser 1978, Strauss 1987), clearly directed at the manageability of a research project. In fact, as Schreiber (2001) points out, Glaser and Strauss identified more than one core category in their original study. They resolved the problem by publishing two books (*A Time for Dying, Awareness of Dying*) addressing a core category in each book, thus elegantly evading the issue of compliance with their own formulated requirement of one core category in GT research.

Whether the development of a core category is really essential must be questioned. Settling on one central category bears the danger of underestimating the role of other important factors (Dey 1999), resulting in a too narrow analytical focus in ignoring processes and behavioural pattern evident in the data and their importance in understanding the bigger picture. It therefore might be impossible to reduce what is going on in an area under investigation to one core category. Like Charmaz (2000) I

was unable to identify one core category that encapsulated the multiple processes identifiable in the data that captured the experiences of families and nurses during a critical illness. Forcing the data into one core category would have seriously violated the trust both groups had in me to listen and represent their experiences.

Saturation of concepts

The theoretical saturation of concepts marks the ending point of data gathering and analysis. Theoretical saturation of the core category is the criterion upon which the ending of sampling is based. Saturation of concepts is defined as ‘no additional data are being found whereby the sociologist can develop properties of the category’ (Glaser and Strauss 1967:61). Whilst this sounds logical just how this judgment is reached remains unclear (e.g. Dey 1999, Charmaz 2000). The elasticity of this concept is evident in practice where it is obvious that the researcher has to make some pragmatic and rational choices as to when a category is saturated. Flick’s (2002) solution of stopping and reflecting on what one has got, listing results and balancing them within a priority list and then deciding which codes need further development in the light of the original research question, is a pragmatic approach to theoretical saturation. It is also one which makes the process transparent and links it back to the logic of theoretical sampling and sensitivity.

Both Charmaz (1990) and Flick (2002) point out that theoretical saturation is difficult to achieve since the researcher will always be left with questions regarding his or her data and therefore theoretical sampling could result in never-ending integration of further cases. In the end, the depth and extent of data gathered and analysed must be sufficient to enable the researcher to tell a plausible story (Melia 1997).

Data collection in this study involved interviewing groups. Focus group interviewing was the guiding method in this process and is addressed in the following section.

Interviewing families and nurses as groups

One way of tapping into the social network participants live and work in is through group interviews. Group interviewing is a qualitative data gathering technique that questions several interviewees simultaneously in formal or informal settings (Fontana

and Frey 1994, 2000, Bryman 2004). While Lofland and Lofland (1995) suggest that group interviews should be used as a supplement to individual interviewing, others argue that a study design can be based on group interviews alone (Merton et al. 1990, Frey and Fontana 1991, Morgan and Krueger 1993, Kitzinger and Barbour 1999). Some authors distinguish between different forms of group interviews, for instance, brainstorming, focus groups, Delphi technique or group discussions (e.g. Mendes de Almeida 1980, Frey and Fontana 1991, Green and Thorogood 2004, Fontana and Frey 2005) whereas contemporarily all group interviews are often generically referred to as 'focus groups' (Fontana and Frey 2000).

In relation to the first issue, namely group interviews as a supplement or stand alone method, the design decision needs to reflect the rationale for using group interviews. Interviewing groups as opposed to individuals might be seen as a limitation by some and it has to be acknowledged that group data differ from individual data. My decision here is based on the assumption that individuals in a group make sense of social phenomena through interaction and discussions with each other and thus construct meaning in their every day lives. The group interviews method is perceived as particularly effective in exploring participants' experiences and knowledge about a specific topic but also how and why people think the way they do (Kitzinger 1995, 1996b, Morgan 1997, Kitzinger and Barbour 1999, Flick 2002). Individual interviews, in contrast, explore important personal issues (Rubin and Rubin 2005). Hence, individual interviews would not tap into group processes that influence the experiences, attitudes and perceptions groups hold in relation to a topic.

Concerning the second issue, namely the generic reference to focus groups for different forms of group interviews, Morgan (1997) argues, as does Fern (2001), in favour of an inclusive approach, adopting the term as a 'broad umbrella' or 'big tent' that allows for variations where the particularities of focus group interviews are determined by the research project rather than the other way round. Further, Morgan (1997) points out that methods like Delphi technique do not involve group interviewing anyway hence fall outside definitional boundaries of group interviewing. Focus groups interviews were adopted for this study.

Focus groups

Historically, focus groups emerged from the techniques used in focused interviews of individuals and groups developed by Merton and coworkers (Merton and Kendall 1946, Merton 1987, Merton et al. 1990). Morgan's (1997) chronological reflection dates the beginning of focus groups back to the 1920s and the American sociologist Emory Bogardus' description of group interviews. The method was implemented in market research by Lazarsfeld and colleagues during the time of World War II and has been used in that area ever since. The rediscovery of focus groups within social science dates back to the 1980s (Madirz 2000). Its current popularity is evident in a high number of publications on the issue (e.g. Morgan 1993, Greenbaum 1998, Barbour and Kitzinger 1999, Krueger and Casey 2000, Bloor et al. 2001, Fern 2001, Puchta and Potter 2004) and its frequent use in research including nursing research (e.g. Nyamathi and Shuler 1990, Stevens 1996, Robinson 1999, Murdaugh et al. 2000, Whyte et al. 2000).

Defining focus groups

Reflecting the popularity of the method, there are many definitions of 'focus groups'. Morgan, for instance, defines focus groups as 'a research technique that collects data through group interaction on a topic determined by the researcher' (Morgan 2002:141), while Tonkiss defined them as 'a small group discussion focused on a particular topic and facilitated by a researcher' (Tonkiss 2004:194). Krueger and Casey describe five features of focus groups:

(1) people who (2) possess certain characteristics and (3) provide qualitative data (4) in a focused discussion (5) to help understand the topic of interest (Krueger and Casey 2000:10).

In essence, all definitions have as their main feature a set topic as a focus for the discussion and the importance of interaction between research participants. It is the interactions between participants that provides access and therefore insight into how social knowledge is produced (Green and Thorogood 2004). It is exactly this access to the co-construction of meaning, processes and norms within groups (e.g. Carey 1994, Kitzinger 1994, 1995, 1996a, Bloor et al. 2001) that is sought in order to understand

the social processes relating to families in ICU. The underlying assumption of this approach is that opinions are not always available at the beginning of the interview but are open to influence by others during an interaction (Albrecht et al. 1993, Kitzinger and Barbour 1999, Tonkiss 2004). Consequently, focus groups are not a means to arrive at a consensus or group decision making, team building and so on (Krueger 1993) but very much a technique to tap into the social network:

‘in which people might normally discuss (or evade) the sorts of issues likely to be raised in the research session and the ‘naturally occurring’ group is one of the most important contexts in which ideas are formed and decisions made’ (Kitzinger and Barbour 1999:8-9).

In order to employ focus groups successfully a number of methodological issues must be considered.

Methodological considerations

There are major differences in the way focus groups are used in market as opposed to social science research. Discussion on this topic can be found in a number of writings (e.g. Morgan and Krueger 1993, Reed and Payton 1997, Kean 2000, Whyte et al. 2000, Krueger and Casey 2000, Webb and Kevern 2001, Puchta and Potter 2004). It is evident in many articles in nursing and social science that the popularity of focus groups have led at times to an uncritical adoption of market research guidelines, for example, regarding group size, group composition and so on. Kitzinger and Barbour (1999) point out that adopting rather than adapting guidelines from other disciplines bears the danger of undermining the potential of this method. In the following discussion my focus is exclusively on the application of focus groups as I adapted it for this study in reference to the groups of interest.

Group size

Group size is one of the issues that is rather prescriptive in market research but needs adaptation in social science research. Experiences from a previous study using focus groups (Whyte et al. 2000) had taught me that interactions in smaller groups (around 6 participants) flowed successfully while interactions in bigger groups (up to 11 participants) were at times somewhat difficult to establish. Not surprisingly others

have reported similar experiences (Mansell et al. 2004). In a method that uses interactions as means of producing data small groups are clearly preferable.

In response to this insight and in relation to nurses I adopted Watts and Ebbutt's definition of a group which states that:

'a group we take to be a congregation of more than two interviewees at a time' (Watts and Ebbutt 1987:25).

As a result, the lower boundary for the nurse groups was set at three participants while the upper limit was set at six participants.

In relation to families this issue was handled flexibly in that I accepted the family as unit as it defined itself and thus did not influence the size of participating family units. This also reflects my expectation that contemporary families would be of a manageable size.

Group composition

Participants need to share some commonalities or experiences related to the research topic since it is their experiences one wants to access. Here, the need for homogeneity is a frequently found argument in the nursing literature (e.g. Dilorio et al. 1994, Asbury 1995, Goss 1998, Sim 1998) while others argue that this depends on the research context (Watts and Ebbutt 1987, Kitzinger 1995, Krueger 1998, Kitzinger and Barbour 1999). While I concur with the latter view, groups in this study were homogeneous in that families shared the experience of critical illness, while nurses shared their experiences of having families present in the ICU.

In this context, Fern (2001) refers to group cohesion. Group cohesion reflects those factors that lead individuals to participate in a group discussion of which a shared experience is one example, while gender, professional background, age and so on are other possible variables. Logically, group cohesion is influenced by group composition through sampling.

Power asymmetry in groups is another important aspect that needs consideration in sampling for focus groups. Power asymmetries in families have been discussed above, while power differences in the group of nurses relates to power that is linked to a specific job position (Forsyth 1999). Having experienced the failure to control for this variable in one focus group in a prior study, where a participant was overheard saying to her colleague while leaving ‘now you know what you are supposed to do’ in relation to a policy which was defended by a superior during the discussion (Whyte et al. 2000), I decided to control for power asymmetries through sampling along nurses’ Grades. The importance of controlling groups along Grades or positions is further underlined in the study by Mansell and colleagues (2004) who report a similar incident to ours and the negative impact this had on group discussion in their case.

Group interaction

Group interactions, verbal and non-verbal, are at the heart of data analysis. Ideally, there is a co-researcher who records non-verbal behaviour of group participants (Kidd and Parshall 2000). Degree research is not usually a team activity and hence this was not the situation in this study. I adapted to this circumstance by controlling group size, writing reflective notes on each discussion which included significant observed behaviour (e.g. seating arrangements in families, challenges and reactions in group discussions) and first thoughts on the discussion directly after each interview. These data were entered as field notes into the data set.

Moderator

The function of a moderator or facilitator differs significantly between market and social science research. Both terms are used interchangeably in the literature. While it can be argued that facilitator and researcher are identical roles (Kingrey et al. 1990), I propose that the very term of moderator clashes with what is required in qualitative interviewing. A moderator *controls* a group while a facilitator *facilitates* a group (e.g. Bloor et al. 2001). In this respect, the researcher needs interviewing skills relevant to qualitative interviewing such as listening, probing, being reflective and sensitive to the situation and people involved.

Ethical considerations

A number of ethical considerations, as they apply to research in general, have already been discussed above in the context of family research and young people. Therefore, my focus here is on specific issues as they relate to groups.

Ethical conduct includes the assurance by the researcher that participants' contributions are handled in confidence and their anonymity is observed. In group interviews this promise is compromised by the very fact of the group situation (e.g. Copeland and White 1991). The potential danger here is not the breach of this promise by the researcher but by other interview participants. Consequently, this issue needs to be, and was, addressed before the interview and an agreement was reached with all participants to observe the individual's right to confidentiality and anonymity. In addition, a consent form was signed by each participating individual where the right to confidentiality and anonymity was included (see Appendix 3).

Further, researchers doing group interviews need to be aware that there are questions and issues which can not be asked or probed since this would compromise an individual's right to privacy, confidentiality or anonymity (e.g. Copeland and White 1991, Dale and Altschuler 2006).

Critique of focus groups

No method is without disadvantages and focus groups are no exception. Basch (1987), for example, points out that less articulate individuals are disadvantaged in group discussion. Group discussions can also discriminate against people with communication or hearing disabilities (Basch 1987, Kitzinger 1994).

Perhaps the major drawback of focus groups is the potential danger of censoring and conformity (e.g. Frey and Fontana 1991, Carey 1994). Carey (1994) describes such an incidence in relation to a group of HIV positive military personnel. Conformity, on the other hand, can result from an individual's need to adjust to other contributions and thus conform to the perceptions of others. While one can never be absolutely sure that censoring or conformity does not occur, in particular if there are silent participants, one

way of tackling this potential danger is in encouraging participation through probing. This is not solely a problem of group interviewing but of interviewing more generally.

Frey and Fontana (1991, 1993) suggest that a further disadvantage is that group interviewing requires different skills since the researcher must be sensitive to group dynamics. It is somewhat peculiar that this should be regarded as a disadvantage rather than just different skills required for two different interview techniques. This viewpoint only makes sense when individual interviewing is viewed as a 'gold standard'. Clearly a focus on group dynamic is important for a successful focus group as was underlined in Carey's (1994) example.

Critique of grounded theory

The notion that 'grounded theory' is one of the most abused phrases in the qualitative health literature (Green and Thorogood 2004) is supported by the argument that many of the research contributions claiming to use GT are in effect descriptive studies (Becker 1993) owing to the fact that key methodological issues in conducting GT are ignored.

Becker (1993) identifies some common pitfalls such as failing to use theoretical sampling, not identifying the problematic situation from the data, not using SI as a theoretical perspective, analysing data after finishing data selection and finally, using computer programs to identify core categories based on frequency. Wilson and Hutchinson (1996), examining studies claiming to have used a GT approach, add to this list identifying problems such as a premature closure of data analysis, where findings remain on the descriptive *in-vivo* level of data instead of the concept level or the analysis remains so generic that concepts can apply to 'anything and everything'. Additional pitfalls these authors mention relate to importing concepts from other disciplines which result at times in a failure to suspend preconceptions, disciplinary perspectives or prior knowledge thus ignoring the necessary theoretical sensitivity and the open mind required to do GT.

Epistemological assumptions regarding different versions of GT have been addressed earlier in this chapter. The glossing over of epistemological assumptions is

consequently another danger in doing GT research (Charmaz 1990) and the failure of a researcher to identify their own position has often been criticised (e.g. Charmaz 1990, Stern 1994, Wilson and Hutchinson 1996, McCann and Clark 2003b). It seems therefore self-evident that good research provides an account of what was done when and why in order to enable readers to judge the quality and trustworthiness of the work.

Summary

In this chapter I have given a detailed account of the approach taken to this study, its background, methodological and theoretical position and method used and discussed in relation to the method chosen the data generation, management and analysis procedure.

Constructivist grounded theory was the methodology chosen to examine families' experiences during critical illness and nurses' perception of families in ICU. In choosing a GT approach I made use of systematic, yet flexible guidelines for collecting and analysing qualitative data to construct theories 'grounded' in the data themselves (Charmaz 2006:2).

In interviewing groups, access was sought to interactions between participants and therefore insight into how social knowledge is produced (Green and Thorogood 2004). This access to the co-construction of meaning, processes and norms within groups (e.g. Carey 1994, Kitzinger 1994, 1995, 1996a, Bloor et al. 2001) was sought in order to understand the social processes firstly, in families that experience critical illness and secondly, in uncovering nurses' perceptions of families in ICU. Therefore, focus group interviews were the technique chosen for data collection.

Adopting a group approach allowed for the inclusion of children and young people in this study and hence their voices in relation to their experiences of critical illness in the context of their families are brought to light. It is within a constructivist GT approach that multiple realities are accounted for, attempting to understand the complex world of lived experiences from the emic point of view, in order to grasp an actor's

interpretation of a situation (Schwandt 1994) while at the same time acknowledging the researcher's impact on the construction of *a* reality (Charmaz 2000).

The following chapter gives a detailed account of how GT principles and practices were employed in this study.

CHAPTER 4

Study Protocol

Introduction

The following chapter gives a detailed account of how this study was conducted. In drawing on the analogy between an architect's design ideas for a building and a researcher designing a study Hakim (2000) draws attention to the complexity of decision making in arriving at a research strategy. The need for flexibility in qualitative research and therefore the more fluid and open-ended nature of qualitative research complicates this task (Mason 1996).

Utilising grounded theory as a methodology for a study adds further to this design complexity. The open-ended nature becomes evident when determining sampling strategies while designing a GT study. Here, the emergence and saturation of concepts determines the final sample size and consequently, an *a priori* sample size cannot be given. In the same vein, in order for theory to emerge from data researchers are encouraged to defer an extensive literature review until such time as core categories or themes have emerged from the data (Glaser and Strauss 1967). This can conflict with requirements from funding agencies or Universities to include a literature review as part of the research proposal document. Charmaz (2006) suggests that formally required literature reviews for GT studies can be used as sensitising concepts. This is in line with Dey's (1999) argument that one does not enter the research situation with an empty head but rather with an open mind. In essence, while I had an idea about families' experiences in critical illness I also had many questions and hence at the start of the study I did not know in what direction the research process would eventually develop.

Data collection began in autumn 2002 but was suspended from Christmas that year until autumn the following year due to maternity leave. Data collection restarted in autumn 2003 and finished in spring 2005.

The research process

Research setting

The research setting was an ICU unit within an acute National Health Service (NHS) hospital trust in Central Scotland. At the time of the study the unit was classified as a level 3 unit, meaning the unit had only intensive care patients. During the time of the study the unit expanded from eight to ten beds, while nine of these beds were funded. The unit had 64 qualified nursing staff posts, which translated into 80 full and part-time staff and four clinical support workers. While admissions to the unit reflected the focus on patients with neurological conditions, including traumatic brain injuries, patients with other surgical or medical conditions in need of ICU were also cared for.

Positioning researcher in the research process

Positioning and reflecting on my position within the research process is of importance for two reasons. Firstly, the approach taken is qualitative and constructivist in nature. Within a constructivist approach the researcher ‘constructs an image of *a* reality, not *the* reality’ (Charmaz 2000:523) through interactions with participants. This then identifies the researcher as an insider and co-constructor of the data as opposed to an outsider whose understanding is objective, value free and unbiased. In any research context authorship is neither silent nor unimportant (e.g. Becker 1967, Charmaz and Mitchell 1996) and needs to be acknowledged in order to establish trust in one’s findings.

Secondly, having read the literature around families, intensive care nursing and critical illness and being a nurse with experience in this area I was not a naïve interviewer exploring an unknown aspect of nursing. I was, in that sense, an insider. However, being German and having gathered my practical nursing experiences exclusively in Germany, I was at the same time an outsider who was unfamiliar with the finer points and policies of the NHS on a local and national level. It was therefore important to identify myself as a German nurse, which in turn, provided the necessary space to ask questions which otherwise would have been perceived as ‘daft’ or ‘unusual’ for a nurse with my background.

Doing reflexivity

Reflexivity is at the heart of any qualitative inquiry and directly linked to the positioning of the researcher within the research process. Reflexivity is not *a* step but a process throughout the conduct of qualitative research. Its importance in relation to participants' motivations for taking part and the researcher's different 'selves' within a research situation were discussed in the previous chapter. In this section I focus on how reflexivity and my different selves came into play in the real world while doing qualitative research. The underlying reflective process which was employed throughout this study is demonstrated in the following excerpt from a family interview. In this case, Jon had suffered a severe head injury after an accident and Susan (family 4), his mother, was keen to assure her younger children Carrie (18) and Alan (13) that the situation was not hopeless. She waited until the end of the interview before addressing me directly.

Susan: A:hm I know that you have got experience of sort of - intensive care and things (.6) Have you had a lot of experience of people coming through this and really getting back to just about-? (.5)

SK: No. And I'll tell you why, because that was not the unit I was working on.

Susan: Right.

SK: I was working on- we did exactly the same like they do here. I was working on a surgical ICU, and we had them when that was the foreground, whatever it was- the surgical issue was the foreground. But as soon as they were like Jon is now, we would transfer them to more appropriate units like he is now in neuroscience. And that's where they nursed them. You hear about these patients because you keep asking about them. Sure. But it's not that I personally have a lot of experience with these kinds of patient. But what was the question?

Reflective memo: It was clear from the way she was looking (smiling, head slightly tipped), her tone of her voice, slow speech and long pauses that she wanted some kind of confirmation that Jon would get better to just about the level he was before the accident. My suspicion was, that she asked me this question more for the benefit of Carrie and Alan and not for her because she was very realistic about Jon's injuries and what this would or could mean for him and his life. Both Carrie and Alan paid a lot of attention to what I was saying and how I was reacting. I was aware of this and decided to be honest but 'built in' hope as well. I also had the feeling that that was not really the question she wanted to ask.

The last sentences of my memo refer to the discussion that followed the above excerpt in which we discussed the excellent progress Jon had made up to that day. This was the 'built in' hope bit in which I reflected on what the family had told me about Jon's progress up to that day, thus indirectly pointing out to Carrie and Alan that there was still sufficient clinical uncertainty which would prevent any clinician to make a definite outcome statement. In doing so, I emphasised that time was of the essence in these types of head injuries. The element of time was qualified by me in using Jon's voice, which had been an issue earlier in the interview, as an example. In explaining the impact of a prolonged intubation on vocal cords I pointed out that time in this context does not mean next week or in two weeks time but that recovery can take indeed months. Carrie and Alan were very attentive listeners and it was obvious from the interaction that followed between family members that they had been looking for information.

However, in families where the issue of prognosis surfaced during the interview, I acted in accordance with other health care professionals in remaining ambiguous and non-determined. Any other behaviour would have been unacceptable for two main reasons. Firstly, the level of clinical uncertainty prevented even clinicians from making any definite statements about the patient's prognosis and secondly, as an outside researcher and as a nurse I simply was not in a position to make prognostic statements. This then refers to my 'self' as a nurse and the division of labour that exists between nurses and physicians.

Nevertheless, I did act as a nurse, giving information if the information requested was within the remit of nursing. This is also evident in the above excerpt in which I explained the reason and the time needed for Jon's voice or vocal cords to recover from a prolonged intubation. Although I was clear about my role as a researcher, I was aware that I might be seen by others as a source of information since I am a nurse with relevant ICU experience. Another example relates to family 1. Pam's partner had confided in her that he was suffering from nightmares and hallucinations following his extubation. While she was concerned about his behaviour, indirectly asking me if this kind of experience was normal, it also emerged that she had not discussed her concern with any of the ICU nurses. In this interview I drew the family's attention to a

considerable body of literature that suggests a link between sedation and the experiences of hallucinations or delusions of ICU patients (e.g. Jones et al. 2001, Griffiths and Jones 2002, Rundshagen et al. 2002, Ringdal et al. 2006, Corrigan et al. 2007). In doing so, I reframed this family's experience as something that is to be expected in patients after the withdrawal of sedation thus normalising the patient's experience. In finally understanding the interplay between sedation, ICU environment and hallucinations or nightmares the family's relief was visible (more relaxed body posture) and audible (sighs of relief) during the interview. Pam also commented that 'that makes sense' in response to my explanations. At the same time I pointed towards ICU nurses as a source of information and support on this very issue.

There is a very fine line between maintaining a more detached research attitude and the contributions a researcher can make in alleviating families' suffering during a time of critical illness. In these situations there is the real danger of muddling roles in becoming the expert giving advice instead of being a researcher. At the same time, I considered withholding information like the above to be unethical since it would have exacerbated the suffering of family members. My strategy of remaining vague and ambiguous in relation to any prognostic statement or possible outcome but giving specific information on nursing issues in combination with advice to tap into other information sources (i.e. nurses) demonstrates the middle ground in which I managed my different identities in the real world of qualitative inquiry.

Gaining access and ethical approval

Gaining access is a complex multilayered process which happened at the same time as applying for ethical approval from the relevant Local Research Ethics Committee (LREC). These two processes needed to be dealt with simultaneously since the hospital Trust requires ethical approval before it grants access to the area of interest, while the LREC requires access approval before it awards ethical approval. Bearing this in mind, these processes will be discussed in turn.

Gaining access

The formal aspects of gaining access to a clinical area in this study followed a classical top down approach. The process was set in motion by writing to the director of

nursing of the relevant Trust, explaining the study and asking for permission to approach intensive care units within the Trust. The answer was favourable. However, given the sensitivity of the study, the nursing director requested that I discuss the proposed study with senior nursing management prior to approaching any unit and inform the research nurse, whose remit was the coordination of any ongoing research within the Trust, of the study.

Subsequently, the principal nurse of the relevant division and the research nurse were contacted in writing, informing them of the study and asked for a meeting to discuss further details. This resulted in a request to present the study to ICU consultants, ICU nursing managers and charge nurses. While there was a great deal of overall interest in the study, the group was also very protective of families since I wanted to access these families at a time of crisis. In one of the discussions a consultant suggested that I should seek approval from them before approaching a family and this became the established *modus operandi*.

Originally I had intended to access two ICUs within the Trust. Different contact strategies were agreed with the charge nurses of the units. While the smaller unit agreed I should phone twice a week to ask if there was a suitable family, the larger unit wanted me to come in person. The larger unit had almost twice the number of beds as the former and therefore substantially more staff than the 80 staff members in the smaller unit. Consequently, establishing rapport with ICU staff was a challenging undertaking.

The support of the charge nurses in the research unit was crucial to gain effective access to the unit and its staff. In the case of the smaller unit, charge nurses suggested holding a series of information seminars in order to introduce myself and inform staff of the study. It was this informal aspect of gaining access that established a relationship with the staff and resulted in successful cooperation. In addition, we agreed that I would ask for the 'nurse in charge' when phoning for information. With the benefit of hindsight, this arrangement was a key component in establishing rapport with the ICU staff and since this was a smaller group of nurses they were all aware of who I was and what I was looking for.

In the case of the bigger unit, I never managed to gain effective access despite completing the formal process. A number of reasons present themselves for this failure. Firstly, the unit was in the process of moving location and integrating HDU patients into ICU, and thus it enlarged in size. This resulted in the recruitment of new staff and consequently their 'settling in' was given priority since it affected the functioning of the unit. Seminars, like those provided to the smaller unit, were not possible. Secondly, the size of the workforce was itself a drawback. The information on my study appeared to have been lost in the process of settling into a new location with new staff and a changed patient group; on numerous occasions, even asking for the 'nurse in charge' required an explanation of who I was and what I wanted. I had to realise that it would have taken a lot more time to establish a level of contact that would result in the recruitment of families. On a practical level, the entry phone system at this unit was not working on at least two occasions and so despite being there in person, I was simply faced with a locked door and was not able to get the desired information. After discussing the situation with both of my supervisors and taking into account that I was successfully recruiting sufficient families from the smaller unit I decided to withdraw from the larger unit.

Local Research Ethics Committee (LREC) approval

Simultaneously to the process described above ethical approval for the study was sought from the relevant ethics committee. This took around six months. The ethics committee requested the naming of an independent advisor for the study and a clarification on the information leaflets before final approval was given (see Appendix 2 & 3). It was also a condition of ethical approval that the researcher kept the LREC informed about progress for the duration of the study. In accordance with guidelines updates were submitted once a year.

Management approval

In addition to ethical approval the study needed management approval on Trust level. This is an internal process in which the Trust assesses the financial and resource implications of a study on the Trust. This is a process which takes place after ethical and access approvals have been granted, adding to the waiting time before the field can be entered. In this case management approval was given in due course. The study was

also listed on the National Research Register as part of the management approval process after seeking permission from me to do so.

Inclusion/ exclusion criteria

The following criteria were used to identify suitable families and nurses.

Families

Families of interest are those families, where one adult family member has spent at least three days in intensive care and is stable. Families must speak English and include children aged 10 years and above.

Specifically excluded are all families where the patient is dying, expected to die or is unstable. Distressed family members will also not be approached for participation.

For the purpose of this study families were defined as:

A group of persons who share a history and a future and are committed to each other. Individuals define themselves as part of that particular family.

Intensive care nurses

Intensive care nurses with at least six months experience in ICU nursing are invited to take part in focus group discussions. Nurses new to ICU nursing will be excluded.

Recruiting participants

The study was organised into two distinctive phases: firstly, family interviews and data analysis and secondly, focus groups with nurses.

Families

Based on the above inclusion/ exclusion criteria families were identified by the nurse in charge. Following the identification, consultants were asked for approval to approach the family. Sometimes the nurse in charge asked on my behalf while at other times I approached consultants. This process raised the question of consultants as gatekeepers to families. One consultant, for example, remarked that this process actually pre-selects the families I can see. While I agree with this assessment in

principle I am satisfied that their influence on the family sample had no adverse effect in practice. This assessment is based on the fact that they never refused access to a family and my belief that nurses did not withhold information on potential study families. In cases where nurses thought a family should not be approached, they mentioned the family and then argued their case. Often, these were either distressed families or families where nurses felt the patient was not stable enough and might die.

A 'wait and see' policy was adopted in these cases. I inquired about these families in subsequent phone calls to the unit and continuing assessment of the family's suitability for the study took place. Sometimes this would result in families being approached at a later time (for example family 7) while at other times nurses' misgivings proved correct and the patient unfortunately did die.

After the identification of the family and the consultant's approval, I met all families, apart from one, within the ICU area for further discussion of the study, handing out information leaflets and formally asking the family to participate. These interactions themselves provided some insights into the family and their situation. Individual family members clearly had the need to talk about their situation and took the opportunity to raise a number of interesting issues. At times these meetings were with a parent only, in which case issues of their children's coping with the situation were frequently raised. At other times more than one family member was present and these conversations usually addressed the critical illness situation as such. These data were integrated as field notes into the data set once consent was obtained.

Following these first contact interactions, families were given at least 24 hours to consider their participation or non-participation before I contacted the family again to learn of their decision. In general, a great deal of flexibility was required since I needed to adapt contact to families' needs at the time. Sometimes it took time for parents to discuss participation in the study with their children. Distance between the family home and the unit and not seeing their children on a daily basis was a predominant reason for this. However, once all family members agreed to participate a day, time and location was set for the interview reflecting the family's choice.

Intensive care nurses

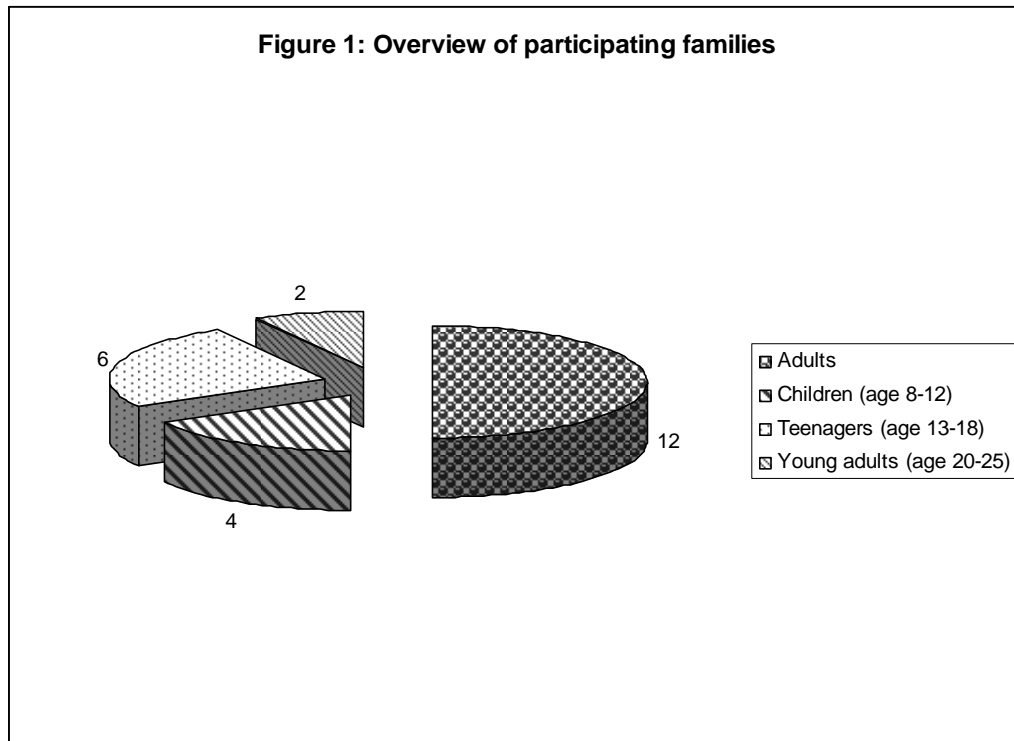
Before recruiting nurses, I had a meeting with some of the unit's charge nurses in which we discussed possible interview locations, times and dates in accordance with the unit's schedules. Charge nurses suggested that focus groups be held during the working day allowing those nurses interested in the study to participate without specially coming in on their days off.

As I argued in chapter 3, it was important to control focus group participation along nurses' Grades and with this in mind, we set dates and times according to the unit's shift plan and thus the availability of nurses. Recruitment sheets (see Appendix 4) were prepared on which dates, times and the grades I was looking for were stated and displayed on the unit. Nurses interested in the study could sign up. There was flexibility needed on my part since it was impossible to predict how busy the unit would be on the day in question. Most scheduled focus groups went ahead as planned but two groups had to be re-scheduled on short notice because the unit was too busy for nurses to attend.

Sample description

Families

The family sample consisted of nine families, with a total of 12 adults and 12 children. In six of the nine families the husband and father was the critically ill patient, while in three further families the adult son was in ICU. Participating adults ranged in age from 34 to 55 with the majority of adults being somewhere in their forties (see Genograms for further details). Patients ranged in age between 17 to 63 years of age, while children's ages spanned from 8 to 25 years. Figure 1 shows the distribution of participants according to age categories.



Further details of families' background and children's school or educational status can be found in individual family profiles.

Non-participating families

Three families which were approached for participation declined. In the first case, the grandmother of a 15 year old teenager was the critically ill patient. This young person lived with her grandmother and the partner of her grandmother but declined to participate because she felt too stressed to 'talk about it'.

In the second case, the patient was diagnosed with Gulliane-Barré Syndrome and admitted to ICU, since he needed to be ventilated. Gulliane-Barré Syndrome is a neurological disorder where the body's immune system attacks the peripheral nervous system. An ascending paralysis is common and can eventually lead to the need for prolonged ventilation of the patient. The need for ventilation is a mark of the condition's severity and in this case patients face a long recovery period. Concurrently to this family, two further families of interest were in ICU and because in both cases the illness was not expected to be as long term as was the situation in the case of the

above mentioned family, I decided to follow-up the other two families before attending to this family. By the time I had conducted both family interviews and followed-up this family, the family was no longer interested in participating.

In the third case, the patient was again admitted to ICU suffering from Guillaine-Barré Syndrome. While the mother of the 10 year old child was very interested in participating, the child declined arguing that she 'doesn't want to talk about it'. Consequently, this family was also lost to the study.

A further family that was approached and had agreed to participate was also lost. In this case, when I arrived at the unit to interview the family I learned that they had just gone home after the sudden death of their family member. This was a sad outcome which emphasised the unpredictability of the critical illness families and nurses face in ICU.

A gendered sample

All patients in this study are male. Efforts to include families where the patient was female failed. During the time of data gathering there were three families where the mother was the patient. However, in all three cases the patient was either too unstable or the male partner too distressed to be approached. As described above, in these cases I had a 'wait and see policy' with a continuing assessment of the family. Two of these three women unfortunately died while in the third case the partner never appeared to fully cope with the situation. He did not allow the children into the unit, despite the fact that they had witnessed the original incident which resulted in the ICU admission. This family, whilst not being interviewed, is nevertheless present in my data because nurses, caring for the mother, discussed the situation of the children in more than one focus group.

Ethical issues of including underage children

The general approach taken to including children in this study has been discussed in Chapter 3 at some length. The age range for which ethical approval was given included children of ten years and above. In the case of one family one of the children was aged eight. Before including this family, the study's constraint on including

children that are younger than the approved age limit by the LREC were discussed with the mother. The mother, in turn, argued that she did not want to exclude one of her children on the grounds of ethical approval given by the LREC since the child was clearly affected by the critical illness situation. She felt that if the child agreed to participate in the study, she should be allowed to do so. In addition, this family had gone through a critical illness episode involving intensive care treatment of a different family member two years prior to the current event. It was this information and listening to the mother's argument that led to my agreeing to involve this younger child in the study.

On the actual interview day I went with the child line by line through the information leaflet as well as the assent form in order to check if the child understood terms like 'confidentiality' and 'right to anonymity' and what I was about to ask. This was without doubt a bright child who could explain terms in her own words and made a valuable contribution to the study in the subsequent interview.

On a more general note, this experience raises a different ethical issue, namely that of excluding children despite their wish to be included because of an arbitrarily set age limit. As discussed in Chapter 2 there is clearly a conflict between accepting children's own agency and their right to decide for themselves and the requirement of ethics committees to define an age limit on inclusion or exclusion.

Intensive care nurses

Nurses in this sample reflect a highly specialised workforce. Overall 20 nurses participated in five focus groups. Seventeen of these nurses were female, while three nurses were male. Out of the 80 staff of this unit, 10 are male thus the gender distribution of the overall workforce is reflected in this interview sample. A more detailed overview of participants is provided in Table 2. Gender is deliberately not identified in this table to protect nurses' anonymity.

Table 2: Overview of participating nurses

Participants	Age	Lengths of ICU Experience	Nursing Grades in Interview Group
1	41	19 years	G
2	39	18 years	G
3	32	10 years	G
4	48	20 years	F
5	40	16 years	F
6	33	10 years	F
7	41	13 years	E
8	35	5 years	E
9	33	6.5 years	E
10	28	5.5 years	E
11	24	4 years	E
12	41	10 years	D
13	41	7 months	D
14	41	5 months	D
15	30	5 months	D
16	26	1.5 years	D
17	50	20 years	E&D
18	34	11 years	E&D
19	29	2.5 years	E&D
20	25	1 year	E&D

Nurses ranged in age from 24 to 50 years of age, with the majority of nurses being in their thirties (n= 7) and forties (n=7). It is evident in the table that there is a correlation between acquired Grade, age and ICU nursing experience gained. While nursing experience ranged between 5 months and 20 years in the overall sample, ICU nursing experience amongst more mature nurses ranged between 10 to 20 years.

In two cases nursing was a second career, resulting in older nurses in their forties. These nurses had less than a year experience in ICU nursing. However, due to their life experiences and family circumstances these nurses differed from younger colleagues in their views on families in ICU.

Organising focus group interviews

Methodological issues relating to focus groups have been discussed in Chapter 3. The following section attends to practical issues which need consideration before focus group interviews can take place.

Environment

There is agreement in the literature that the environment in which an interview takes place has an impact on the data generated (e.g. Greenbaum 1998, Green and Hart 1999, Kitzinger 2004). This raises the issue of whether to interview within or outwith the hospital. In the focus group literature the environment for interviewing is regularly described as one that needs to be soundproof, comfortable, light and friendly, non-threatening and ensuring privacy (e.g. Kingrey et al. 1990, Carey 1994, Kitzinger 1995, Krueger 1998, Goss 1998). Many hospital buildings in Britain are very old and do not have facilities which would meet these requirements. In this case the ICU's family room and the staff meeting room in which interviews were conducted are internal rooms with no natural light.

Families in this study had the choice of three interview locations: their own home, a room within the hospital or my University office. These locations were chosen to allow families to stay at home or enable them to be near their ill family member but also purposefully included a neutral location away from the hospital. Three families chose to be interviewed in their own home, while six families preferred to stay near their loved one and chose the hospital as interview location. No family opted for the University. It was not a coincidence that those families with younger children opted to be interviewed in their own homes. These families were able to combine other domestic activities with their interest in participation and interviews took place around daily family life activities such as having tea. On one occasion I travelled some distance for the interview since the family lived elsewhere.

The interview location for nurses was a pragmatic choice - one of the staff meeting rooms which is used on a regular basis for educational purposes. I had some familiarity with this room since I held the study's introductory seminars there. The location needed to be near the unit since focus groups were held within nurses'

working day. This allowed the unit to have immediate access to participating nurses should the need arise through unforeseen events.

Timing of interviews

The earliest point at which families were contacted was after their family member had been in ICU for three days. This is an arbitrary time frame used in critical care research (e.g. Leske 1986, Norris and Grove 1986, Coulter 1989, Tracy et al. 1999) with the intention of giving families some time for orientation to the unit and time to cope with the critical illness situation before approaching them for research participation. Families in this study supported this time frame to some extent since many argued that the first days were the most difficult. The other important factor affecting timing of contact was the pathophysiological stability of the patient. As described in the inclusion/ exclusion criteria the patient had to be stable. Thus contact times ranged between three days to three weeks after admission to ICU and interviews were held ranging from one to four weeks after admission to ICU. Six out of the nine interviews were conducted while the patient was still in ICU, while in three cases the patient had, literally, just been transferred to HDU.

Catering

For all interviews that were held in the hospital food and drink was provided before the start of the interview. Foods included sweet and savoury snacks and a variety of fruits. Drinks included cold and warm drinks. In the case of family interviews I asked parents about the preferences of their children before, for example, including carbonated sweet drinks.

Participants were asked after the interview if they wanted to take anything with them. This offer was usually accepted. Families were spending prolonged hours in the hospital with little opportunity to access certain foods. It was not surprising that the healthy options like fruits and water were particularly welcomed. Nurses were asked to take remaining food with them to share with their colleagues.

Catering for participants is an accepted part of focus group interviewing. Within market research, participants usually do not know each other prior to focus group

sessions and this time is used to familiarise participants with each other (Greenbaum 1998, Krueger and Casey 2000). In social science focus groups, participants may or may not know each other. In relation to this study, all participants knew each other.

In catering for participants I had two main aspects in mind. Firstly, one cannot expect participants to discuss a topic for an hour without at least having something to drink. Secondly, I used food and drink as a time buffer for participants to settle down into the environment, as a time for some chatting between participants and myself and to distribute demographic data sheets (for nurses) to be filled in and two sets of consent forms, one signed form to be handed back and one for the participant to keep. In nurses' focus groups handing out of both forms was a simultaneous process while in family interviews the development of Genograms containing demographic data of individuals and their definition of who was and was not in their family unit followed the reading and signing of the consent/assent forms. In drawing attention to the recording equipment I pointed out that the interview would be recorded, asked participants to 'take turns' in the following discussion if at all possible and provided a time to clarify any issues relating to 'what happens with the data'.

Seating arrangements

Seating was arranged to allow the omni-directional microphone to pick up the conversation in progress. In the family room I rearranged sofa and chairs so that we were sitting in a semi-circle. On one occasion one of the family members chose a chair away from other family members. Initially I considered asking this family member to change place to accommodate the way I had set up the recording equipment. However, in listening to the pre-interview chat between family members I decided to rearrange the recording equipment and leave the seating arrangement. With the benefit of hindsight, this was the right decision since their seating arrangement expressed individual differences in coping with the situation. While one family member was ready to 'move on' in life, the others were very much in the 'here and now' living from one day to another. Sometimes it pays to experiment with seating arrangements and observe the unfolding story.

For the nurses' focus groups I used the set-up of the room. The staff room is small and had a table with chairs around which served the purpose well.

Recording equipment

It is important to use a high quality omni-directional microphone for group discussions since a normal microphone is unable to pick up multiple speakers. These microphones are very sensitive and this was a consideration when choosing food for groups. I used a Sony ECM-R300 omni-directional microphone with noise reduction. This microphone is small and unobtrusive and it was placed strategically to get the best possible recording quality.

The recording device was a digital Sony IC Recorder ICD-MS515 with a 64 Megabyte memory card. Again, this small hand held device draws little attention to itself. The big advantage of a digital over tape recording is the fact that one does not need to turn tapes in the middle of interviews and thus one loses neither data nor concentration. Further, the interview can be directly copied onto the computer for transcription - the recorder comes with transcription software similar in functionality to conventional transcribing machines.

The equipment was checked again for functionality immediately before use and replacement batteries were at hand.

Interview guide

The focus group interviews were in-depth and qualitative in nature. An initial family interview guide was developed at the beginning of data collection and refined throughout the simultaneous data collection and analysis. The initial topic guide for nurses was based on previously collected family data. In line with grounded theory analysis, topic guides changed considerably over time reflecting emerging themes and the need to saturate categories.

The structure of the topic guide followed suggestions by Kingrey and colleagues (1990) and Charmaz (2002) who describe three phases in the interview: opening, intermediate and ending stage. In general, I made use of open ended questions throughout all three phases of the interview since these questions foster discussions

between participants and elicit views, opinions and so on. Introductory questions such as: ‘Can you tell me what happened...?’ or ‘What was it like....?’ aimed to set participants at ease talking about the topic of interest.

Questions in the intermediate stage were more focused in that they progressed from general to more specific questions. Questions, such as: ‘Can you remember how you felt when...?’ or ‘How was this for you?’ or ‘Who is most affected by X being so ill?’ and ‘How does he or she show it?’ were used.

Ending questions aimed at wrapping up the interview but also gave participants the opportunity to address any issues that were left out and were of importance to them. Some families were asked: ‘What advice would you give someone in the same situation?’ while nurses were asked: ‘From your perspective, how do you think families view ICU?’ In all interviews I asked whether we had touched upon an issue they wanted to explore in more depth or if there was an additional issue participants wanted to raise. Examples of interview topic guides for both groups are included in Appendix 5.

After the interview: helpline and information resources

At the end of family interviews and before saying a final ‘Thank You and Goodbye’, family members were given envelopes with relevant information resources. These were adapted to the individual family’s needs. For instance, a family where a member had suffered a stroke, information resources and support groups were listed which were geographically relevant to this family. In one case, a mother specifically requested information on children suffering bereavement and this was provided. Information gathered in the pre-interview conversation influenced the content of information sheets provided, which as a result were more useful to families.

Each child was given a separate envelope which included helpline and information resources, a ‘last comment’ sheet, a stamped envelope (with my address on it) and also a five pound note. Originally, I had intended to include a phone card of the same value since most children of this age group have mobile phones to enable children to contact any of the information resources. Due to the range of mobile phone services and card

schemes I decided to substitute the phone card for cash and let the children decide how they wanted to use the money. None of the participants knew in advance that children would be given this money and therefore it could not be seen as an inducement.

The actuality of all information resources was checked immediately before they were provided. In supplying a last comment sheet I deliberately provided children with an opportunity to contact me again in confidence if they wished to do so and/ or raise issues they did not want to discuss in front of other family members. This technique had worked in a previous study using focus groups (see Whyte et al. 2000). While children in this study did not take up the opportunity, the reasons for this remain unclear. Appendix 6 contains examples of the information sheets handed out.

Focus group interviewing

The approach taken in this study is one of interviewing groups as opposed to individuals. A major advantage of focus group interviewing is that it provides access to interactions between participants and hence insight into how social knowledge is constructed (Green and Thorogood 2004). Methodological issues relating to focus groups have already been addressed in chapter 3 and hence this section is concerned only with the conduct of focus groups.

When participants arrived I introduced myself, thanked them for coming and offered drinks and food. As described above, the beginning of the session was used for participants to settle down, get something to eat and drink and to provide space for informal conversations. I made a point of asking families how their family member was today, while nurses were asked about 'how things are in the unit' before the official start of the interview, thus establishing rapport from the beginning of the meeting. This time window was also used to get the bureaucratic things done (e.g. informed consent). A major concern for moderators of focus groups is the establishment of a discussion between participants (Krueger and Casey 2000, Bloor et al. 2001). However, while this anxiety is founded for participants who do not know each other, the situation for participants in this study was markedly different. They were either family members or colleagues and thus knew each other well, hence informal conversations flowed easily.

The official beginning of the interview was marked by my formal introduction of the purpose of the interview and in setting ground rules for the discussion. These rules included taking turns, the confidentiality of individuals and respect for each other. Groups were informed that I was looking for a discussion amongst participants and this was contrasted with a question and answer type of interview.

The switching on and off of the recording was audibly commented on and groups naturally could observe this action. Nurses were asked to briefly introduce themselves since although there was a seating map of participants I needed a way of identifying speakers on recordings to aide transcription. This was a particular issue in nurses' focus groups due to the number of adult females and similarities in voice quality which made it difficult to distinguish between speakers on recordings.

To ease into the interview family interviews started with the general question of what had happened to their family member, while nurses were asked what they saw as their role with families in ICU. The prior developed topic guide identified areas of interest and was used as orientation at the beginning and as a fall back mechanism in case I lost the thread during an interview.

The group interviews were qualitative and in-depth in nature. Rubin and Rubin (2005) point out that qualitative interviews are conversations in which a researcher gently steers the conversational partner into an extended discussion. The same principle can be applied to group interviews. Whether that is the case depends on the conduct and involvement of the moderator or interviewer. The involvement of the interviewer can differ significantly in focus group interviews and depends on their purpose. In qualitative research using focus groups as method the interaction of participants is of interest, hence the degree of interviewer involvement is of importance. The moderator can either control group discussions and thus group dynamic or allow free participation (Morgan 1997). The 'low moderator involvement' focus group is consistent with qualitative social science research (Morgan 1997) and was adopted in this study.

The unpredictability of group discussions (Krueger and Casey 2000) requires a high degree of flexibility from the researcher in exploring the views and perceptions of

multiple members and in responding to emerging themes. In an attempt to foster a variety of views and opinions I pointed out at the beginning of interviews that I was interested in the range of participants' experiences (Morgan and Krueger 1993). I often observed the unfolding story as opposed to questioning and probing every contribution. Observing allowed for the identification of less vocal participants and deliberately bringing them into the discussion by directing a question or probe to them. Directing a question to a particular participant is also a strategy for eliciting differing viewpoints (see Myers 1998, Puchta and Potter 2004). This strategy at times triggered opposing views to be voiced, giving discussions a new impetus and direction.

Pause and probe

Pause and probe are two useful techniques in interviewing and as Bloor and colleagues (2001) point out using silence is a well documented prompt in interviewing. Krueger and Casey (2000) recommend the five-second pause before the interviewer intervenes with a follow-up question or a probe. Pauses quite often prompted other participants to voice additional points of view, agreement or additional information. It is important to observe the group in their interaction in order to get an idea why pauses arise. Sometimes pauses represent the time needed by an individual to recall events before contributing to the discussion. At other times, pauses mark an ending of a discussion sequence before a group moves on to another topic. It is paramount for the researcher to allow groups this time for collecting their thoughts before intervening with follow-up questions. The strategy of staying in the background and waiting to see what happens paid off in a number of interviews, generating highly significant and interesting data. In one family interview, for example, a family started to discuss their emotional turmoil and anger at the patient, assigning responsibility for the accident to him after a longer pause. This then provided insight into this family's coping in relation to clinical and functional uncertainty related to the patient's brain injury. In the end, one needs to be bold enough to allow pauses and experienced enough to know when a pause is a genuine indication that an intervention is needed to keep the discussion flow going or that it is time for summing up and ending a session.

Probing is the second technique used in interviewing. Probing is essential in group interviewing in order to clarify individual's positions and views. In one focus group,

for instance, a nurse commented that ‘nurses are often annoyed with families’. While there was some verbal and non-verbal agreement this is such a vague statement and open to various interpretations that some clarification was needed. Hence, I probed in asking ‘if she could say a bit more’ which in turn, triggered an interesting discussion providing insight into nurses’ views and experiences with families in ICU. In relation to statements like the above it is also essential not to be judgemental but accept them as the view of an individual. Participants also observe interviewers and react in turn to their observation. Hence, there is a correlation between the interviewer’s conduct, the trust and feelings of security that participants develop during an interview and the data one is able to gather.

Writing observational notes

The focus in interview studies is often on the researcher and therefore I minimised writing notes during the session in order not to appear distracted or uninterested in the ongoing conversation. After the sessions however I wrote extensive notes, writing down observations I had made, brainstorming about initial impressions of interviews and recording any thoughts that came into my mind. Schatzman and Strauss (1973) distinguish between three forms of field notes: observational, methodological and theoretical notes. Observational notes only record statements of observations; theoretical notes contain an element of analysis in reflecting on observations and asking analytical questions while methodological notes address methodological issues pertaining to the research situation. My notes predominantly recorded observations but also contained theoretical and methodological elements where needed thus representing a mixture of these three note forms. Field notes entered the data set providing useful background information for analysis and constructing ‘the bigger picture’ scenario.

Sampling strategy

Purposeful sampling is the strategy used in GT research allowing the ‘inquiry into and understanding of a phenomenon *in depth*’ (Quinn-Patton 2002:46, *Italic in original*). Theoretical sampling as utilised by grounded theorists has been discussed in Chapter 3. The idea behind theoretical sampling is to explore emerging themes with subsequent participants and thus saturate categories. Theoretical sampling as a strategy is based

on the constant comparative method, hence the concurrent analysis and collection of data, and consequently starts with the first data gathered (Glaser 1978). Charmaz (1990, 2000), in contrast to Glaser, recommends theoretical sampling at a later stage in the research process, namely after the emergence of key themes around which theoretical sampling then takes place. This is a more logical approach since data analysis indicates the direction in which theoretical sampling should proceed and thus prevents a premature focus of the study.

Sampling in this study evolved within the same clinical area and is more specific to that area. In looking for 'expert informants' (Glaser and Strauss 1967) I was looking for families who could tell me about their experiences with critical illness in an ICU environment and nurses who had experiences with families in that situation. Theoretical sampling came into play once the first tentative themes, for example, 'ambiguous loss' or 'children's need to be present' emerged from the data. At this point I purposefully questioned families for in-depth information on the identified aspects to either further explore or discount the themes. In addition, I went back to earlier interviews and re-coded, where appropriate, for later discovered processes or strategies. The same principle applied to nurses' focus groups. The mixed grade focus group was, for instance, a result of theoretical sampling. This allowed me to check out of emerging themes in the context of nurses' position within the unit's hierarchy structure.

Simultaneously, and in line with GT procedures, notes were written on various aspects of the research process. The notes took the form outlined above and were in relation to sampling predominately theoretical or methodological in nature. Theoretical notes reflected ideas and possible links between categories and were further developed in conjunction with the modelling function of the NVivo software. Methodological notes in contrast were reflective notes on the research process itself and my experiences of doing group and family research. All notes were included in the data set and informed the development of the analysis and final write up of the study.

Analysis of data

On transcribing data

There is some debate amongst grounded theorists whether it is essential to record and subsequently transcribe interviews verbatim (e.g. Glaser 1998, Stern and Covan 2001, Morse 2001). Glaser (1998) in particular states in no uncertain terms that one should not tape interviews. He argues that what counts is the theoretical completeness which requires no more than one's written notes, everything else of relevance will be remembered by the researcher in due course. Morse contests this view in pointing out that not recording limits:

'the ability of the researcher to use the participants' quotations and consequently the ability of the researcher to truly ground the study' (Morse 2001:8)

The issue of transcribing is more complex than being able to quote verbatim a participant's contribution to substantiate an argument made. Considering the amount of data gathered in any study, Glaser's position, namely assuming that one would remember any relevant information, contributions uttered and so on by a variety of participants while analysing ones notes, seems naïve. Morse's argument, that a study is truly grounded if one can use participants' quotation, is only correct if the quotes used are relevant in explaining social processes. The aim of GT is the identification and explanation of social structural processes in the context of social interaction (Stern and Covan 2001). While one might agree that this is possible through minute note taking by an experienced researcher doing one-to-one interviews, recording and transcribing interviews increases accuracy and thus the study's rigour.

Krueger (1998), albeit in the context of focus groups, raises a similar issue but clearly links the question of transcription to the analytical rigor of a study. He suggests four options for analysis: transcript-based, tape-based, note-based and memory-based analysis. These options represent a continuum from the most rigorous and time consuming to the least rigorous and less time consuming methods of analysing group data.

The discussion in the context of GT refers to individual interviews while Krueger (1998) represents a view associated with market research focus groups and so both

situations differ from the one faced in this study. Doing qualitative group interviews, as a single researcher, the only option to build a credible database is to record interviews. Recording in this sense might refer to voice or video recording sessions. It is the volume of data in group interview situation which, in my view, makes recording necessary. Consequently, the notion of taking notes as an adequate means of recording group interviews was rejected. The group interview situation is simply too complex and fast moving. Accordingly, all interviews were audio recorded and transcribed verbatim. The original transcripts included transcription symbols that marked pauses, laughter, overriding speech and changes in tone or volume and so on (see Appendix 7). In addition, I used the memo function in NVivo to write reflective notes and analytical thoughts during this process. Transcribing group interviews is a very time consuming task but clearly aided the depth of analysis and, as a result, increased the rigour of the study.

Computer Assisted Qualitative Data Analysis Software (CAQDAS)

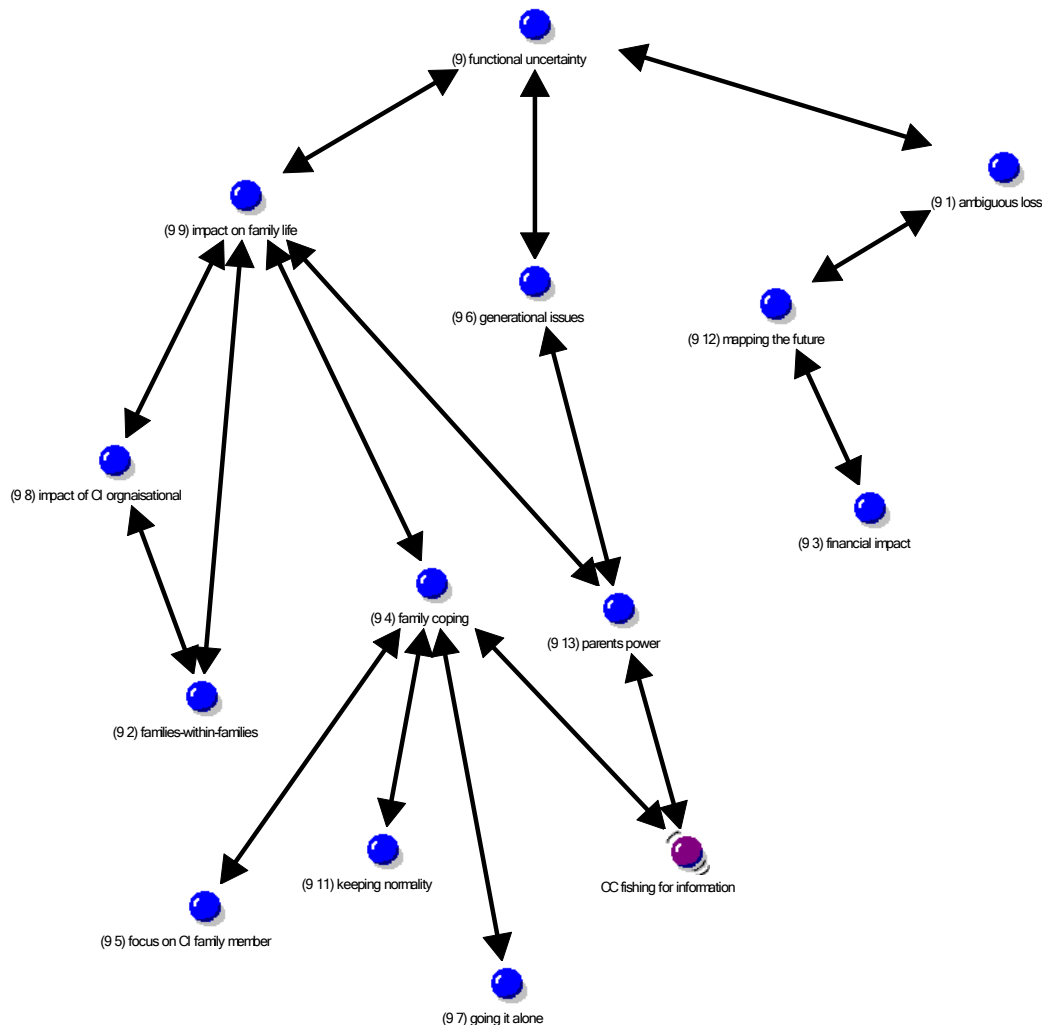
A considerable body of literature discusses the advantages and disadvantages of software packages for qualitative data analysis (Tesch 1991, Dey 1993, Richards and Richards 1994, e.g. Catterall and Maclaran 1997, Weitzman 2000, Seale 2000, Woods and Roberts 2000, Bringer et al. 2004). There are a number of different computer packages on the market of which some were designed with a particular analytical tradition in mind (e.g. Ethnograph for ethnography, NUD.IST or NVivo for GT) (Woods and Roberts 2000).

NVivo 2.0, as used in this study, is usually regarded as the updated and extended version of NUD.IST. Gibbs (2002) however suggests that the programs differ to such an extent that they represent two different software packages. It is evident in NVivo that its design is strongly influenced by GT and supports individual steps within GT analysis well. There are some rather unhelpful changes in terminology. Codes, for example, are called 'nodes' and categories are conceptualised as 'trees' under which a coding hierarchy can be built up and stored.

One has to bear in mind that CAQDAS tools do not analyse data but rather are tools to store, organise, retrieve and link data and it is these aspects of NVivo that were applied. In this respect, the word ‘analysis’ in the title of these programs is misleading and should be substituted with ‘management’. I used the program as a ‘pick and mix’ to suit my purposes rather than letting the program dictate the organisation of my analytical work. Interviews were transcribed and along with all field notes transported into the NVivo database for storage and coding.

The NVivo modeller was used to provide a graphical depiction of the structure of the developing analysis. I found this particular function helpful in visualising and thinking about the relationships of codes to categories and links between codes or between categories. In trying to understand the above relationships I made use of the modeller function creating different models and through this various perspectives on my codes and categories. These exercises required me to think on different levels in search of the rationale which supports or refutes a relationship between codes and/ or categories. Data in the form of print outs supported this process. Figure 2 is an example of how the modelling function was used in conceptualising links and hierarchies amongst codes when thinking about ‘functional uncertainty’ in this study.

Figure 2: Emerging model of functional uncertainty



Coding in a software package is literally at the click of a mouse button. While this makes coding easy, it also bears the danger of a ‘coding frenzy’ resulting in endless lists of codes. Defining the properties of developed codes and regularly going through the code list and the definitions of codes is therefore paramount to keep the analysis meaningful. Codes which were similar in definition were either merged or further refined to underline the different aspect they represented. The program also supports the writing of memos and memos can be directly linked with data extracts or attached to categories and so on. This feature was helpful in keeping track of the ongoing analytical thinking required and also supported writing up the study.

In the context of focus groups, Catterall and Maclaran (1997) raise the important point of the more explicit data fracturing in computer programs during analysis. If the researcher relies on extracts only during the analysis process, he or she runs the risk of creating a situation where there is a restricted data overview and important interaction processes are missed. The strategy in this study of using the full transcript and the identified text units as printouts was successful in keeping both the moving picture and the snapshot of individual and group contributions in focus.

Unit of analysis

The confusion between the individual and the group as the unit of analysis, is according to Morgan (1995), a problem unique to focus group research. While I largely agree with Morgan's argument, I believe that this is not just an issue in focus group research but in all studies involving more than one participant at the same time. Not surprisingly, a very similar debate pertaining to the unit of analysis can be found in family nursing research (e.g. Gilliss 1983, Uphold and Strickland 1989, Feetham 1991, Gilliss and Davis 1992, Robinson 1995b).

Analysing qualitative group data is on the whole the same as analysing other qualitative data with the added dimension of the group context (Carey 1994, Kitzinger 1996b). Focus groups are conducted with the purpose of exploring people's knowledge and experiences in relation to a given topic. The underlining assumption of the method holds that group processes help people to explore, clarify and reflect on their own views and that these views are more accessible through the group situation than they would be in individual interviews (Kitzinger 1996b). There is however a difference in data collected when individual interviews are compared with focus groups. This difference cannot be classified in terms of 'truth' or 'accuracy' but rather reflects different types of discourses (Kitzinger 1994, Michell 1999). Michell (1999) provides powerful examples of the difference in data she gathered using both focus groups and individual interviews to gain an insight into how a changing peer group structure influences the health behaviour of 11 and 12 year old young people. It appears from her report that personal feelings such as being bullied or not belonging to the 'top girls' group were only disclosed in the privacy of one-to-one interviews, while

the discussion in focus groups evolved around the structure of peer groups and its inherent hierarchies.

The focus on interaction in focus groups has led to the assumption that the group has an undue influence on the individual's ability to voice their independent view. Janis (1972) introduced the term 'groupthink' which relates to the conformity of an individual to a group and has been addressed in Chapter 3. Fern (2001) draws attention to the difference between independence and interdependence of participants in focus groups. Independence is the degree of freedom with which an individual functions as a member of a group, while interdependence relates to the 'mutual dependence or being dependent on each other' (Fern 2001:132). Both aspects are factors in focus groups. Participants do express their independent views but also react in an interdependent way to views expressed. It is precisely this aspect of group discussions which is so exciting. Naturally, this has consequences for the unit of analysis. I followed Kidd and Parshall's suggestion that:

[] neither one is *the unit* of analysis, whereas either or both might be *a focus* of analysis. The trick is to devise analytical approaches sufficiently flexible to identify any undue influence of the group on any individual participant(s), or vice versa, before drawing one's conclusion (Kidd and Parshall 2000:299, *Italic in original*).

This implies going forward and backward between two levels of analysis: namely that of the individual **and** the group. In other words, and to borrow a phrase from Catterall and Maclaran (1997), seeing and coding 'the moving picture as well as the snapshot' enables the researcher to gain a more holistic picture and understanding of focus group data.

Data analysis

The ongoing debate about how the analysis of GT data should be approached has been discussed in Chapter 3. To reiterate, while Strauss and Corbin (1998) prefer a three-step coding scheme fracturing data to a maximum, breaking the data apart and conceptualising every single bit before reassembling them, whereas Glaser (1978, 1992) and Charmaz (1990, 2000, 2006) two-step coding scheme allows for a more

holistic approach to data in that the identification of patterns and processes remains the focus. Glaser explains:

We do mean comparing incident to incident and/or to concepts as the analyst goes through his data. We look for patterns so that a pattern of similar incidents can be given a conceptual name as a category, and dissimilar incidents can be given a name as a property of a category, and the compared incidents can be seen as interchangeable indices for the same category (Glaser 1992:40).

In relation to focus group data, analytical procedures vary according to their purpose. Knodel (1993) points out that little has been written about analytical strategies especially in relation to social science focus groups. Morgan (1997) argues that in qualitative studies using focus groups, the general procedures for analysing qualitative data in social science apply. The focal point of analysis in focus groups rests on the interaction of participants (Kitzinger 1994, 1995, Carey 1994, 1995, Morgan 1995, 1997, Bloor et al. 2001). Consequently, a quality criterion of focus group reports is inclusion of group interaction extracts.

My orientation in analysing group data reflects the Glaser and Charmaz approach in seeking out patterns and processes. The general approach to coding evolved around sequences of discussion as opposed to line-by-line but also included single words or lines if these raised analytical ideas and were thus relevant to the emerging categories. While coding I asked the data ‘what is happening here?’ or ‘what is this incident about?’ Coding data and analysis moved forward and backward from the group to the individual perspective by constantly comparing incidences within and across groups. This process was carried out by using print outs of interview data and the computer screen, displaying the interview to be coded. The importance of moving between these two levels is underlined by Morgan when he argues that:

[] we must recognise not only that what individuals do in a group depends on the group context but also what happens in any group depends on the individuals who make it up (Morgan 1997:60).

This stance is linked to the unit of analysis as discussed above. Reed and Payton (1997) provide an interesting example, outlining the impact of moving between the two levels on their understanding of data. It is clear from their discussion that the breaking up of data in CAQDAS and retrieving these fractured data pertaining to a topic led to a confusing picture with little analytical value. The strategy in this study of using the full transcript and the identified text units as printouts was used to circumvent this problem. It was in the context of discussion sequences that processes evolved and understanding followed.

As outlined in Chapter 3 coding moved from open coding to higher levels of abstraction, leading to the building of coding trees under which categories and subcategories were subsumed. In line with Charmaz's (1990) suggestion codes initially remained active, reflecting actions and experiences of family members or nurses such as 'looking for information' or 'giving information' or 'being present' and so on. In addition, I attached memos to group interactions when, for example, a view was challenged and a change of mind had taken place. Here, the importance of post-interview written observational notes becomes evident. Integration of observations helped to keep track of the interactional aspects of group interviews and enhanced data analysis in that it provided a context for a discussion sequence.

By using the modeller function in NVivo a number of different models around core themes were created. Seeing and thinking about relationships between codes and categories and their subsequent hierarchy helped to reflect and clarify my thinking thus raising the abstraction level of the analysis.

Writing was another strategy for focusing my analytical thinking. Wolcott (2001) advises the qualitative researcher to start writing from the beginning of the research. He asserts that writing reflects thinking, in fact 'writing *is* thinking' (Wolcott 2001: 22, *Italic in original*). I started writing once the first models were created and originally used the models as orientation. This exercise forced me to reflect on current stages of the analysis, indicated gaps in data and influenced future probing in interviews and it also triggered the re-examining of already gathered data. Identified themes were further explored in subsequent interviews and the literature and their fit tested in

connection with the emerging analysis. For instance, it became evident that the critical care family needs literature could be linked to some data while other areas identified in this instrument were irrelevant to this study. The need ‘to be near their loved one’ is one example which was substantiated over and over again in interviews, while the need ‘to explain the ICU environment’ was marginalised to such an extent that one has to question whose need that really is: the families or the nurses?

In essence, the analysis does not cease with the development of an analytical framework but proceeds into writing (Mitchell and Charmaz 1996, Charmaz 2000, Wolcott 2001). In this context, Charmaz (2000) suggests a number of strategies for writing grounded theories. These include the use of simple and straight forward language, the use of analogies and metaphors to illuminate feelings and experiences and positioning the writer in the background as storyteller ‘whose tales have believable characters, not as an omniscient social scientist’ (Charmaz 2000:528). In writing from a constructivist perspective and employing principles and strategies of grounded theory I offer in the following chapter my explanation of the data without claiming that this is the only possible interpretation. Alternative interpretations of the data are clearly possible. However, based on theoretical sensitivity and theoretical sampling I suggest that the analysis offered in the following chapter is a particularly plausible one.

The absence of a core category

The aim of a GT study is the identification of a core category (e.g. Glaser and Strauss 1967, Glaser 1978, Strauss and Corbin 1998). The core category represents a selected central or core phenomenon that accounts for most of the data and thus brings prior developed categories together in a coherent whole (Dey 2004). In fact, Glaser (1978) argues that without identifying a core category the GT drifts in ‘relevancy and workability’. He reiterates this point in a later work, saying that:

[i]n order to accomplish this goal grounded theory tries to understand the action in a substantive area from the point of view of the actors involved. This understanding revolves around the main concern of the participants whose behavior continually resolves their concern. Their continual resolving is the core variable (Glaser 1998).

As discussed in Chapter 3, Glaser and Strauss had faced the dilemma of having identified not one but two core categories in their seminal work on dying. Glaser and Strauss circumventing the issue by creating two publications but this luxury was not available to me for this research. Charmaz (2000) was also unable to identify a single core category. In this research the same problem emerged and I was unable to identify one core category that encapsulates the multiple processes identifiable in the data and captured the complexity of experiences of families and nurses during critical illness.

Arguably, I could have ‘artificially’ created a core category of ‘clinical and functional uncertainty’ since data exist in both data sets which would have justified such a move. The consequence of this would have been the marginalisation of structural systems related processes that influenced the experiences of both groups to such an extent that an overall understanding of the experiences of families and nurse in relation to critical illness would have been compromised. Further, this would have also been in direct contradiction to the principle that GT tries to understand the action within a selected area from the perspectives of actors (e.g. Glaser 1998). Delimiting the study to such an extent would have resulted in ‘shallow, thin and insignificant’ research (Morse 2002).

This issue may have arisen because I made the ‘mistake’ of including two different groups of actors (nurses and families), representing two different systems, with very different interest in the same social space. Yet, reflecting on my research questions, an implicit aim of this study has always been the identification of possible nursing interventions. Why would one want to do research if it has no practical consequences? Logically, including nurses is necessary since nurses are the ones who implement change and thus their views need to be taken into account when identifying if and what changes or interventions could and should take place.

Whilst this approach created the two core category (clinical and functional uncertainty and nursing in public) dilemma, it also allowed for a different level of insight than a focus on a single ‘clinical and functional uncertainty’ category would have supported and advanced my understanding of the care of families in ICU beyond these concepts. I came to realise that there is a central thread running through all three analytical chapters. While this does not satisfy the criteria for a core category in that the majority

of data account for it, it pinpoints the problematic integration of two systems within a shared social space of the ICU and the impact this is having on the experiences of all actors during a critical illness. This thread running through all three analytical chapters provides the context for identified major themes and thus represents the conceptual link between chapters. The negotiations and integration of systems necessary to meet the needs of both families and nurses is consequently the overarching theme that emerged in relation to all three data sets (families, children and nurses).

Whether the study therefore can be formally termed a grounded theory must be left to the judgment of the reader. In any case this is a qualitative piece of research which made use of the principles and practices of grounded theory as has been discussed and outlined in the previous and current chapter.

Issues of quality in qualitative research

Evaluating the quality of qualitative research is a complex and debated area (e.g. Creswell 1998, Flick 2002, Green and Thorogood 2004, Seale 2004b). Green and Thorogood (2004), for example, offer a list of ‘good practice guidelines’ that enhance the credibility of an analysis. Criteria that illustrate rigour include writing a transparent account of procedures used, the analysis of the whole data set including deviant cases and the inclusion of data to enable the reader to judge the researcher’s interpretation, the comparison of data within and across cases and a reflective account of the researcher’s role in the study. These criteria resemble good research practice and need to be explicitly addressed in any study. However, one needs to bear in mind that issues of quality and credibility overlap with the intended research purpose and audience, which in turn, results in a situation where ‘philosophical underpinnings or theoretical orientations and special purposes for qualitative inquiry will generate different criteria for judging quality and credibility’ (Quinn-Patton 2002:542). Hence, quality criteria between different research traditions vary.

In relation to a constructivist GT, Charmaz (2006) suggests the following criteria:

- **Credibility:** Has the research achieved intimate familiarity with the setting or topic? Are the data sufficient to merit your claim? Has the study provided

enough evidence for the reader to form an independent assessment of your claims? Have you used systematic comparisons between observations and between categories?

- Originality: Do the categories offer new insights? What is the social and theoretical significance of this work? How does the GT challenge, extend or refine current ideas?
- Resonance: Do the categories portray the fullness of the studied experiences? Do the findings make sense to participants or people who share their circumstances? Does the analysis offer them a deeper insight about their lives and worlds?
- Usefulness: Does the analysis offer interpretations that people can use in their everyday worlds? Can the analysis generate further inquiry in other substantive areas? And finally, how does the study contribute to knowledge?

In essence, the problem of assessing the quality of a study is transferred to the level of writing and reporting in that the research report needs to present and reflect on a plethora of methodological processes (Flick 2002). It is in the writing up phase that a reflective dialogue between the author, intended audience and the text is created in telling a plausible story that goes beyond data analysis by arguing for its plausibility and relevance for other stakeholders.

Summary

In this chapter I gave a detailed account of how this study was conducted. Issues and experiences that emerged through the open-ended nature of GT research and ways I dealt with them were addressed. Involving two groups had the effect that there was time for me to reflect and think about data gathered from the first family group phase before moving on to the second phase with the nurses' groups.

A consequence of having two groups which I had not foreseen at the time of designing the study was my failure to determine a core category. Instead of limiting the study to such an extent that an overall understanding of both groups would have been

compromised, I remained true to the study's constructivist underpinning of listening to the voices of all participants and accepted that there would be no single core category. The following chapters bring to light these voices from the perspective of families, young people and the views and experiences of nurses in working with families in intensive care. '*Clinical and functional uncertainty*', '*Young people's experiences with critical illness and their strategies to access information*' and '*Nursing in public*' are the major themes that emerged from the data.

In exploring a little researched area, I made use of existing ideas and concepts where appropriate as well as identifying links between sociological concepts in creating new insights into the experiences of families and nurses in intensive care. While concepts such as 'clinical and functional uncertainty' or 'negotiated order' and so on will be recognised by the reader, Glaser points out that through 'theoretical coding, in establishing new connections that make ideas (however recognisable) relevant, is what is so often the 'new' and 'original' about theory' (Glaser 1978:72).

This then is the contribution of this work: making new connections and developing a theoretical understanding based on major themes that are grounded in the perspectives and experiences of families and nurses during a time of critical illness requiring intensive care therapy.

CHAPTER 5

Family Profiles

Introduction

In this chapter I introduce the participating families in more detail. Families are introduced visually using Genograms and written family profiles. This part of the thesis is based on the *Calgary Family Assessment Model (C-FAM)* (Wright and Leahey 1994, 2000, 2005). The C-FAM was particularly helpful in understanding how families were structured, interacted with each other or functioned in relation to each other during critical illness. My understanding and use of C-FAM is briefly outlined below.

The Calgary Family Assessment Model (C-FAM)

The C-FAM is a multidimensional framework based on a number of theories including systems theory, cybernetics and communication theory (Wright and Leahey 1994, 2000, 2005), which I argue, are compatible with Grounded Theory, Symbolic Interactionism and Constructivism (see Chapter 3).

The model consists of three major categories: (1) structural, (2) developmental and (3) functional, which are further redefined in a number of subcategories. I agree however with Wright and Leahey's (Wright and Leahey 2000) view that the use of subcategories should be discriminate and relevant to the family in question rather than following obediently a list of questions to ask a family. Consequently, in the following section I define my understanding and the use of categories and subcategories of C-FAM, as it was relevant to my study population.

Structural Assessment

The structural assessment addresses the internal, external and context aspects of a family. Subcategories of internal aspects are family composition, boundaries and subsystems. I include all three subcategories in the Genogram developed with each family at the beginning of the interview.

Genograms are a versatile tool and as McGoldrick and colleagues (1999) point out can be used in a variety of contexts (e.g. medical history, genetics, family therapy, nursing and so on) and for a number of purposes (e.g. for assessing, planning, intervening or gaining an overview). Genograms can contain a vast amount of information that goes well beyond structural, relational or boundary information and might include, for example, life cycle transitions, changes and challenges a family experienced, beliefs, myths, rules or behaviour pattern of a family and so on (e.g. McGoldrick et al 1999). In other words, Genograms can be adapted to the users' needs in terms of simplicity or complexity.

My own use of Genograms in this study is pragmatic in that I use them as an assessment tool to gather information on family structure and relationships between individual family members. The end product is a Genogram that provides a quick graphic overview of structures, boundaries and relationships of a particular family at a specific time.

In order to reflect the diversity of families today I asked family members to define who is in their family. More often than not family members stated the obvious, in naming biologically or emotionally linked and/ or attending family members as part of their family. I followed this up with questions relating to any other person(s) who is/ are important to this family and could be considered as being part of the family. Relevant others were then included in the Genogram. Further, it was not uncommon for children to include pets in their family definition (Halldén 1994) and where this was the case, pets were included in Genograms.

Using a family group approach in defining 'family' resulted at times in the identification of more than one family unit. For participating families three main reasons emerged for differences in 'their' family definitions:

1. A family member had a close friend who he or she considered to be part of his/ her family but who was linked only to this particular family member.
2. The family was a blended family.

3. There was a family conflict in the background.

From the structural assessment these families appeared to have multiple families within their family. I named this the ‘families-within-family’ phenomenon. The implications of this phenomenon are diverse. In the first case scenario, where a close friend was part of the family but was linked to one individual in the family (e.g. Family 2) or where several family subsystems existed (e.g. Family 4), individuals drew together to support each other at a time of uncertainty.

In the second case scenario, the implications of differing family definitions had important ramifications on how individuals coped and handled the critical illness situation. In this scenario the families-within-family phenomenon differs from subsystems in a very important way. I understand the function of subsystems as being related to shifting the focus from the unit level to subsystem level in a particular family unit. Importantly, this does not exclude other family members from a defined family unit. This particular ‘families-within-family’ situation however represents distinctive family units within a family. The function of this phenomenon in the second case scenario is the active exclusion of some family members from another family unit. This phenomenon was particularly evident in families where there was a conflict in the background. The importance of this phenomenon is reflected in the dynamic of experiences families went through while one family member was in intensive care (see individual family profiles).

Boundaries

The C-FAM subcategory of ‘boundaries’ was used in different ways. Firstly, to define the current family unit and secondly, to define a subcategory within a family unit, e.g. in the case where relevant others related only to a specific person within the family unit (for example family 2) or to define ‘families-within-family’ units (for example family 9) and thirdly, to define participants of the interview. Interview participants were marked in a different colour on the diagram.

Extended Family Members

The external assessment aspects relates to extended family members or other larger systems (e.g. school, church, friends etc.). A number of participating families were living in 'blended' families and therefore a former partner and biological parent to a patient or children from a previous marriage/ partnership had to be notified and/ or kept informed of the patient's critical illness.

Context

Wright and Leahey define context as the explanation of

'the whole situation and background relevant to some event or personality.'
(Wright and Leahey 2000:80)

This assessment aspect then deals with the background information and current situation of a family. It includes information relevant to the family that cannot be deduced from the Genogram and further, it explains some aspects of the Genogram in more detail and, in a way, 'sets the scene' for data analysis.

Developmental Assessment

Developmental aspects within my study framework address issues in the 'here and now' as well as the past relevant to families' experiences in intensive care units. In addition, future as well as current challenges of individual families are evident in this section.

Family Functioning versus Reflection on Family

Wright and Leahey's work is situated in family therapy which often uses functional family assessments as a means to understand families. Within the C-FAM family functioning consists of two subcategories: (1) instrumental functioning, which relates to daily family living activities and (2) expressive functioning including aspects of emotional, verbal and non-verbal communication, beliefs, roles, problem solving behaviour and so on.

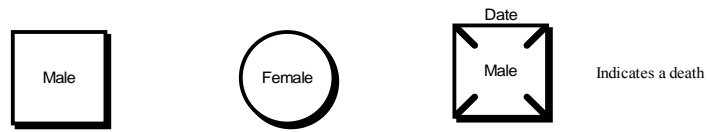
These functional aspects of family life however fail to inform us about what families actually do together (Cheal 2002) and it was this aspect of what families do during a critical illness (process aspect) that was of interest to me. Consequently, a family functioning assessment did not take place in this study. Instead, I offer my reflective understanding of participating families which was informed by what I was told by families and my observations of family interaction.

Genogram Symbols: used and explained

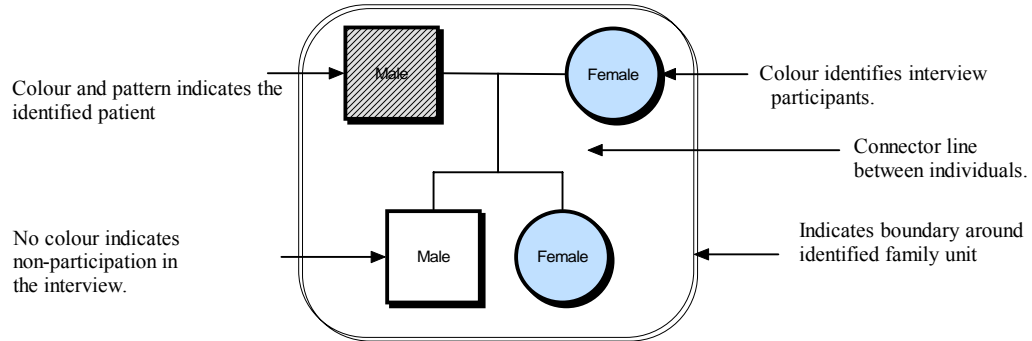
The following diagrams explain the use of Genogram symbols in this study. All names are pseudonyms.

Figure 3

Gender Symbols

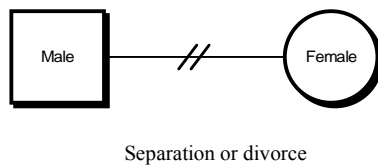
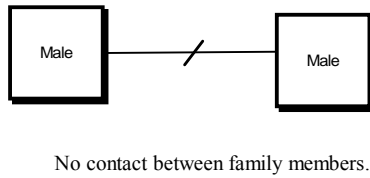
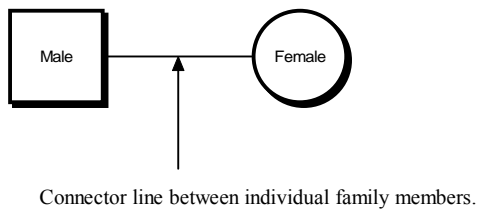


A family unit with children



Children appear from left to right in age descending order.

Meaning of lines used

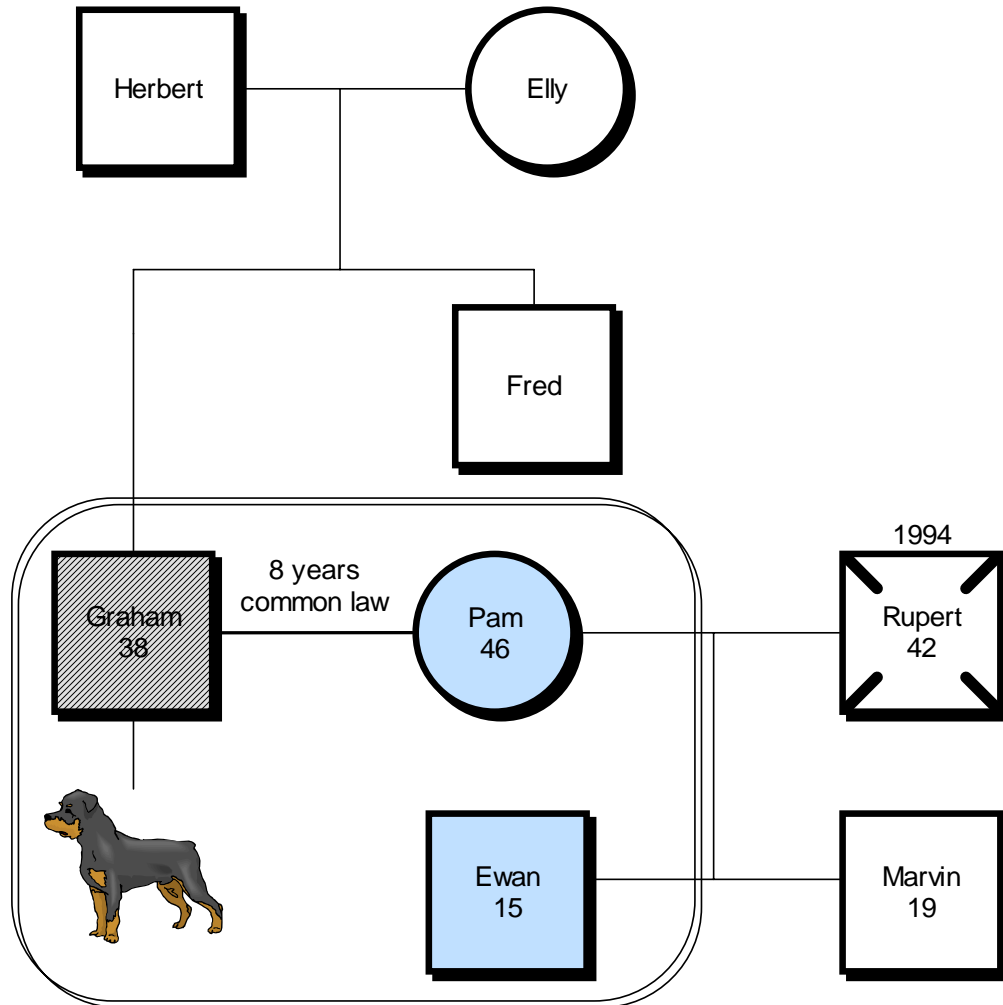


Following are the individual family profiles of participating families.

Family 1

Family Composition

Figure 4



Family Context

Pam (46) and Graham (38) had lived in a common law relationship for over eight years. Pam worked as a chef in their local town and was the breadwinner in this

family. She had two sons, Ewan (15) and Marvin (19) from her previous marriage, of whom only Ewan remained living at home.

Pam's first husband, Rupert (42) was epileptic and died suddenly in 1994. She was keen to emphasise that she did not take any support during her time of grieving but worked through it herself. She also commented that she would do the same again should the situation occur. Pam does not have a driving licence. She could however rely on friends to drive her to the study hospital or she used public transport.

Graham (38) was the identified patient in this family. He had been treated for liver cancer prior to his current critical illness. He had been made redundant some three years ago. Graham's family of origin consisted of his parents, Herbert and Elly, and his older brother Fred who were in contact with his current family. Fred had taken over the responsibility of keeping his parents informed thus relieving Pam.

At the time of the interview Graham had been in intensive care for three and a half weeks and had just been moved to another intensive care unit across the city where he was successfully extubated. He continued to make good progress during the time of our contact.

Family Development

This family was in the process of adapting and coping with Graham's post ICU behaviour. Pam reported that Graham had confided in her that he had lost time and was suffering 'terrible dreams' and was 'seeing images and faces'. He also accused her of having an affair and wanting to leave him. This greatly upset Pam. Both Pam and Ewan had not spoken to anyone, e.g. nurses, about this phenomenon and had no idea why Graham might suffer 'terrible dreams' and hallucinations.

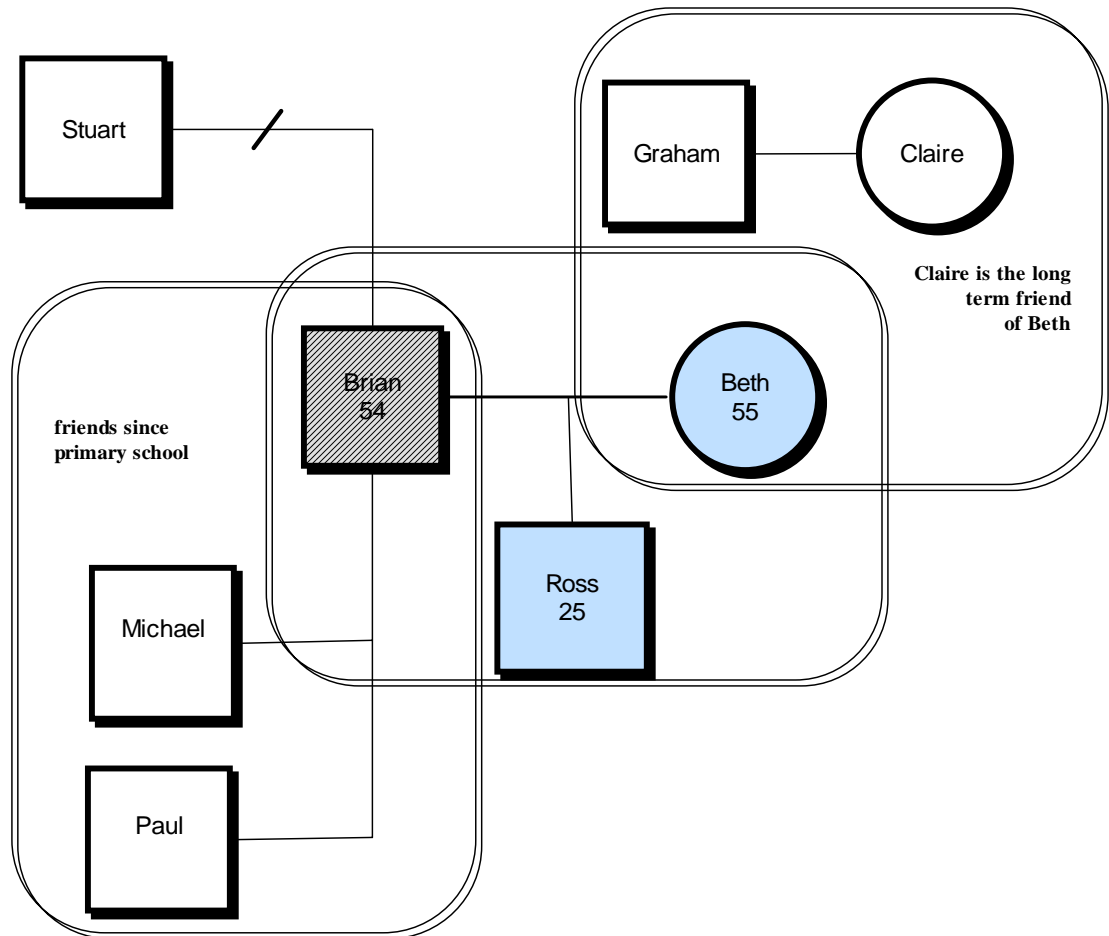
Reflection on Family

Pam and Ewan seemed to support each other during the time of Graham's crisis and beyond. During the interview their communication was open and respectful of each other. Ewan insisted on staying home from school in order to be able to support his mother wherever possible. Pam expressed the view that it was important to include children and give them the support and information necessary to cope. Ewan emphasised that it was important to him to be accepted by adults (including nurses) and not be 'left out'. It was in fact Ewan's idea to take part in this study and thus have an opportunity to voice his views and experiences. The three identified family members seemed to be close and caring for each other.

Family 2

Family Composition

Figure 5



Family Context

This family consists of Brian (54), Beth (55) and their son Ross (25). Last year Brian and Beth decided to take a year out and travel around the United States. In preparation for this extended leave, both had resigned their previous positions at their respective companies. Brian had two very good old friends from his primary school days while Beth stayed close to a friend and her husband throughout the years. While both sets of friends were family friends, they can be linked to one particular individual in the family unit. This is one example of the families-within-family phenomenon, where boundaries are drawn around friends of individual family members. There was no contact between Stuart, Brian's brother, and the family.

Ross (25) is the couple's only son. He had dropped out of university twice and was working for a big Scottish company as a temporary measure before returning to education.

Brian is the identified patient. At the time of Brian's health crisis, Beth and Brian were in the process of settling in again. He had just started working for his old company while Beth, who used to work for a big insurance company, was working for an agency. According to Beth, they enjoyed their 'time out' very much and she talked about it with fondness (e.g. we visited New York – Brian's favourite city.)

The family is very open towards research and expressed more than once that they would like to help me with my research. At the end of the interview Ross commented that talking about his dad's situation had relieved some tension he was feeling.

Family Development

Brian's health prior to this incident had been fine. Although he had suffered a heart attack at the age of 36, he had fully recovered without any long-term effects. When being asked to participate in a medical 'young heart disease victim' study, he agreed. It was due to his involvement in this study that he had been checked out the previous week (blood pressure, cholesterol etc.). None of the parameters gave any reasons for concern. His sudden heart attack (arrhythmia) came as a surprise for which no plausible explanation could be found.

The suddenness and seriousness of Brian's illness clearly came as a shock to this family. It was hard for both of them to come to terms with what had happened and what the future might hold. It became clear during the interview that Beth and Ross were at different stages of acceptance but nevertheless in the process of adjusting to an ambiguous loss.

Reflection on Family

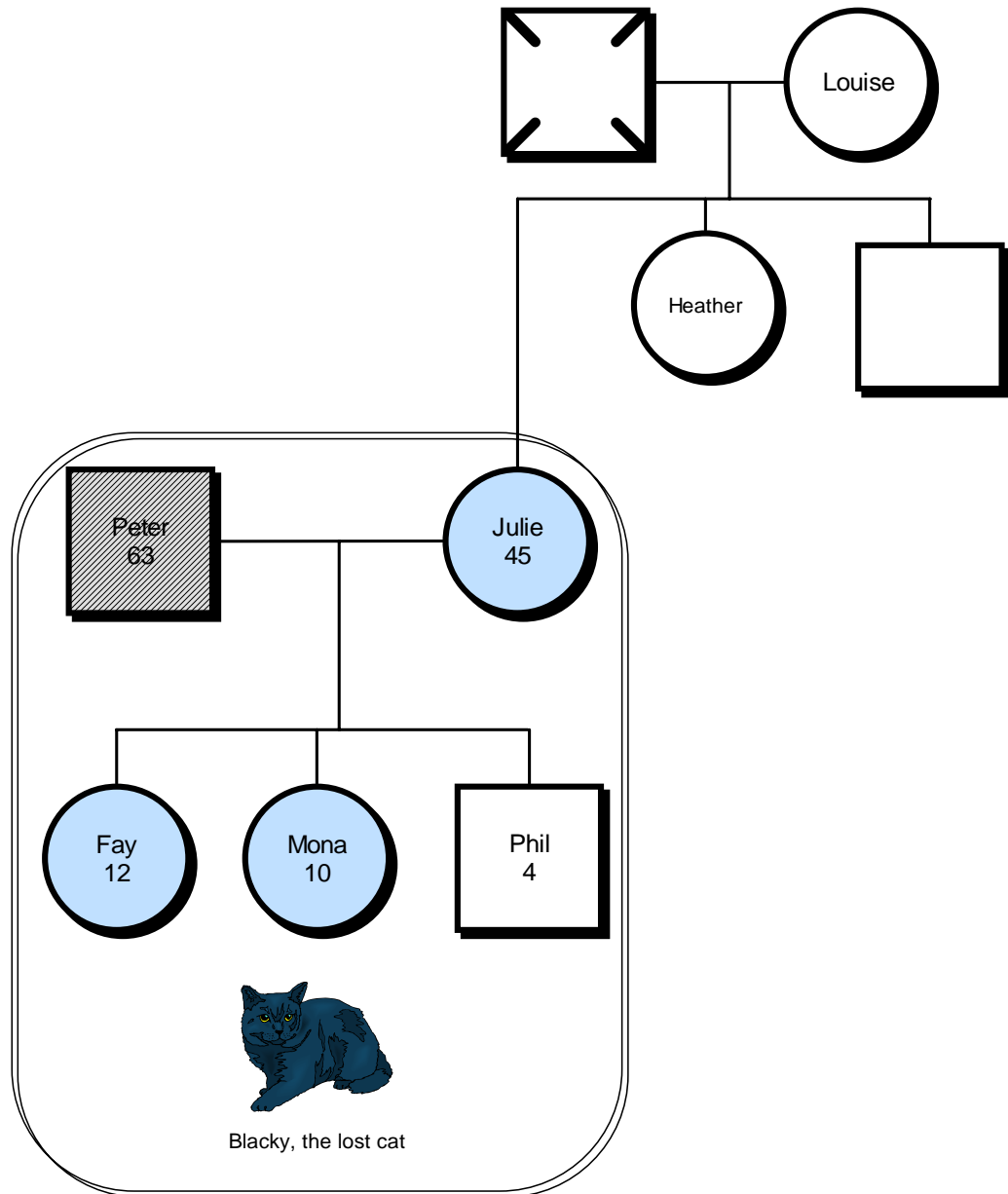
Ross (25) and Beth (55) seemed to communicate their thoughts and feelings in an open and reflective manner, which might have enabled Ross to challenge Beth's beliefs about a number of issues of which the brain scan issue can serve as an example. Beth expressed more than once that she wanted Brian to have a brain scan. It was her belief that it would help in determining the extent of Brian's brain damage. Ross however pointed out that only traumatic brain damage could be identified by a scan but not brain damage due to hypoxia. The identifiable circular communication pattern in this family interview led to a situation where Beth in the end let go of the idea of a scan after accepting the differences of cause.

Further, it appeared that due to his age, Ross's role within the family, goes beyond being a child and includes that of a supportive adult. It was evident during the interview that Beth was drawing on this support and valued Ross's input. His orientation towards the future might help Beth in moving on and coping with what is coming.

Family 3

Family Composition

Figure 6



Family Context

This family consist of a professional couple, Peter (63) and Julie (45) and their three children: Fay (12), Mona (10) and Phil (4). Julie travels regularly overnight during the

week while Peter usually travels once per month for a week or so. At these times Julie's mother Louise, who lived nearby, came and stayed with the children. Fay and Mona described Peter as the parent 'who looks after us' when Julie is travelling.

Peter had two adult children from a previous marriage. Alexander (35), who was living overseas, and Rose (29), who was living elsewhere in Britain. Both had visited their father in ICU.

Heather is Julie's younger sister. She and Louise were supporting and helping Julie in caring for the children. Louise had been caring for the children when the accident occurred. It was also Louise's decision not to tell Phil that his father had been admitted to hospital. Julie was visiting Peter several times a day, which was possible because of the family support she received. Mona and Fay accompanied her alternately on some visits.

Peter is the identified patient who had suffered a severe head injury after falling at their home. At the time of the interview he had been on ICU for 13 days and was still critically ill. It was assumed that Peter had suffered lasting brain damage due to the severity of the head trauma. The extent of the brain damage was unknown at the time of the interview.

Family Development

The suddenness and severity of the accident had shocked this family. Individual family members were still struggling to accept the accident. Adjusting to the situation was difficult and challenging due to the uncertainty surrounding the situation.

Reflection on Family

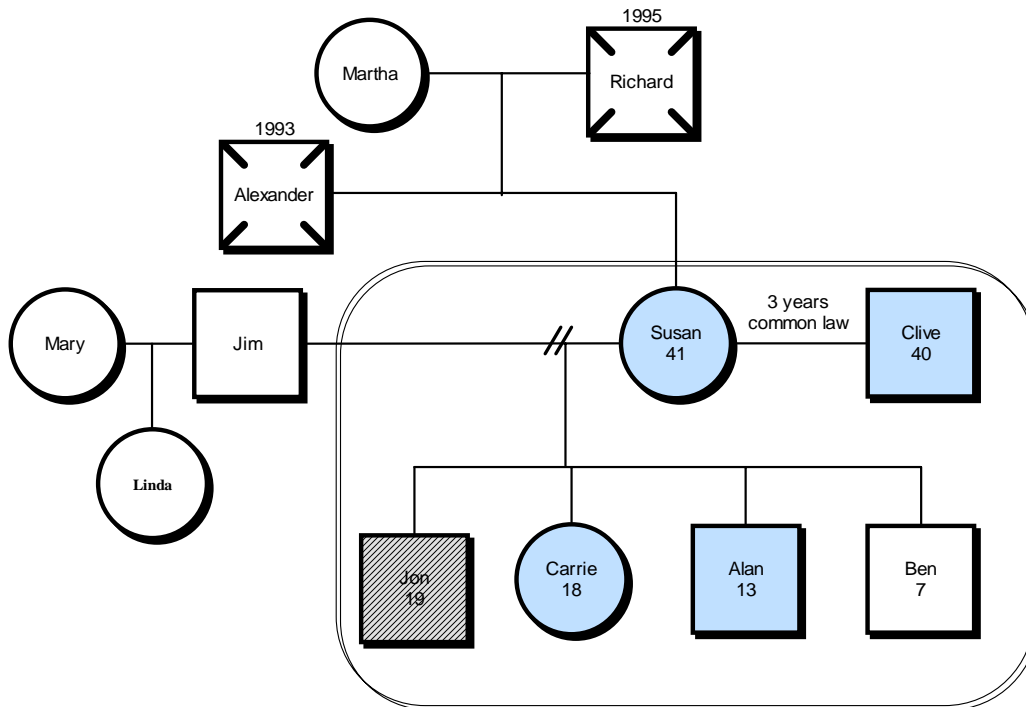
Family members appeared to communicate their thoughts and feelings in relation to day-to-day life well. At the same time the observed interactions suggested that the critical illness had altered the way adults communicated with children. Louise, the grandmother, had withheld the fact that Peter was admitted to hospital from Phil altogether, while she had told the girls that 'dad was really, really ill.' Julie, their mother, stressed that she found it difficult to find the 'right' time to tell Phil what was going on after this 'white lie' had been told. Despite several opportunities during the interview Julie also chose to withhold information from Fay and Mona. Both Mona and Fay presented themselves as outgoing and self-confident girls, which were interested and curious in the world around them, including the ICU.

It became evident in the interview that communication in this family was guided by adults in their attempt to protect the children from the stresses of critical illness. This however failed to acknowledge the information needs children have in this situation.

Family 4

Family Composition

Figure 7



Family Context

This is one of the families in which not a parent but an adult child (Jon, 19) was the patient. The family presented itself as a blended family. Susan and Jim were divorced and had four children: Jon (19), Carrie (18), Alan (13) and Ben (7). Jim had remarried. He and Mary had one daughter. Susan lived in a common law relationship with Clive. Carrie, Alan and Ben were the children living with her at the time of Jon's accident. Susan worked as a support worker and was the breadwinner in this family.

At the time of the accident Jon had not lived with his family. Jon was first admitted to the local hospital before being transferred to the study site. He had been the victim of a 'hit and run' accident which left him with a severe brain trauma and a broken leg. Jon spent over 3 weeks in ICU before being transferred to an HDU.

This family had gone through some traumatic experiences prior to Jon's accident. Alexander, Susan's brother, was murdered some 10 years ago. Two years later her father died of cancer. Martha, Susan's mother, had cared for her husband till his death. She had just moved near to Susan's house and was therefore able to look after the younger children while Susan and Clive were staying with Jon. Susan said that her

way of dealing with the current situation was influenced by ‘what we have been through. As a family - you pull together.’ She said that ‘it was not ‘easier’ but it helps you to find a way forward’. These particular prior experiences set the scene for the way family members coped with the current situation. Susan drew strength specifically from her mother and Clive – excluding her children. This created a situation where adults were ‘in the know’, while the children struggled to get the information necessary in order to cope effectively with the situation. At the same time Susan was very protective of her children and adopted a strategy of gradually releasing information in order to manage the impact of critical illness on them. It was however her ‘information management’ which left the children without sufficient information. In fact, both children used the interview as an opportunity to get information on Jon’s current status. Susan, in contrast, used this interview, as a way of telling and reassuring Carrie and Alan that Jon, no matter what, would always be their big brother. Susan and Clive emphasised the need that the family needed to ‘pull together and support Jon to go through this.’

With Jon recovering and making good progress an element of anger about the circumstances of the car accident in which Jon was the only victim came to the fore. The family was very upset to learn that the ‘lad was known to police and already had a sheet of prior driving uninsured and without licence’. The young man’s mother and grandmother had known that he had taken his mother’s car but failed to intervene.

Family Development

This family had multiple tasks ahead of them. While one of the obvious tasks was related to Jon and his recovery process, another task related to dealing with anger and frustration at the circumstances of this accident. It is likely that this family will relive this critical period when the case resulting from this accident comes to court. Another challenging task facing this family related to Carrie and Alan’s coping difficulties.

Carrie and Alan’s coping had been influenced by the lack of information and therefore the inability to fully comprehend what was going on. By withholding information and not being available both had lost their trust in adults. Rebuilding this trust amongst family members is likely to be a major issue for the near future.

Reflection on Family

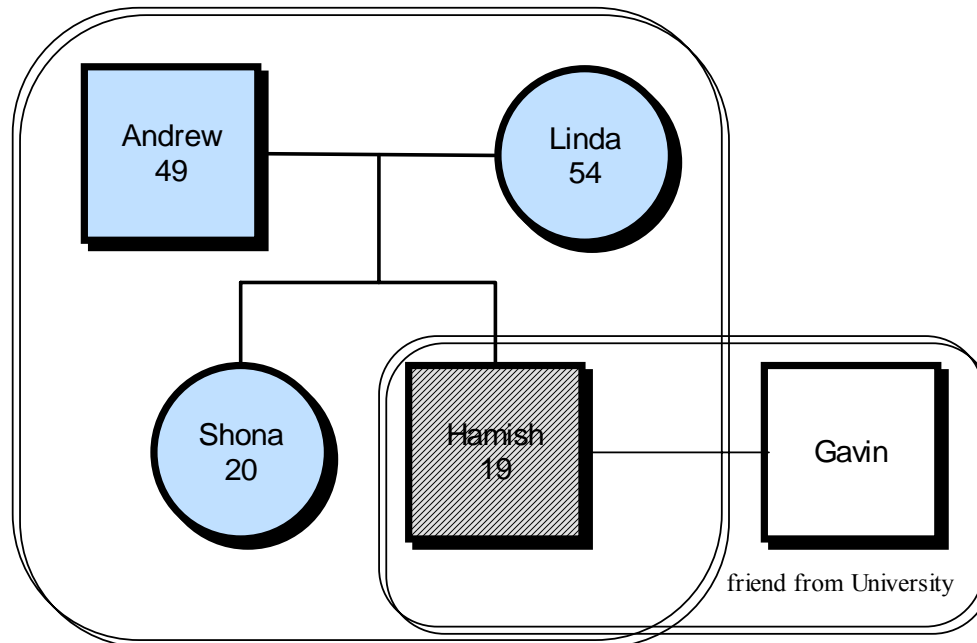
It became evident during the interview that feelings were not openly discussed in this family. Interactions happened along generational lines: adult to adult, child to child but did not sufficiently cross over for individuals to understand the positions of others.

While adults appeared to support each other, Carrie and Alan seemed to be alone within this family unit. Both expressed their understanding of Susan’s need to stay with Jon on a cognitive level, emotionally however they missed her desperately at a time of uncertainty. While Susan and Clive’s emphasised that ‘the family is pulling through this together’, this did not seem to alter Carrie and Alan’s feelings of being left out and alone. It also remained unclear at the time of the interview as to *who* was actually in that ‘pulling through as a family’ unit.

Family 5

Family Composition

Figure 8



Family Context

The identified patient in this family was one of the two adult children (Hamish, 19). The family presented itself as a nuclear family. Andrew and Linda had been married for over 20 years and had two adult children. The family's home was some 70 miles away from the study hospital. At the time of Hamish's accident, both children were students at Universities in different parts of Scotland. Shona was half way through her medical education and at the time of the interview was preparing for a number of exams taking place the following week. Up until his accident Hamish had studied civil engineering.

Andrew was a chartered surveyor and self-employed and the main breadwinner in this family. Linda had, for the past 10 years, been working part time as a school secretary in their hometown.

Hamish had suffered severe head injuries due to a fall from a very high tree (reportedly some 60 feet) and had spent 3 weeks in intensive care. At the time of the interview Hamish had been transferred to a 'normal' ward but had not been in a position to speak about the events leading up to his accident. Family members thought that he had been out on a Friday night and had consumed some alcohol. For some time after the accident Hamish's survival was uncertain. The severity of the brain injury and the real

possibility of a vegetative state raised the issue of withdrawing life support within the family unit. After a family discussion on this issue Andrew asked one physician whether 'it's worth saving him? Because we said there's no point really saving him if he's just going to be a vegetable'. Linda raised the same issue in asking 'do we want him to live?' It was the 'definitely yes' answer of this physician which provided some hope to the family.

Family Development

In the past, Linda had suffered from breast cancer but was now illness free. Shona described the differences in illness experiences in terms of an ability to follow a treatment plan as opposed to 'wait and see' as it was reflected in Hamish's situation.

This family had already launched their children successfully into their adult lives and was now faced with an emerging caring situation.

There are at least two overarching developmental challenges for this family in the near future. The first challenge is the acceptance and coming to terms with their loss of Hamish, as the family knew him. The second challenge referred to the unknown extent of Hamish's possible disabilities and thus the overall impact this is going to have on the family.

Reflection on Family

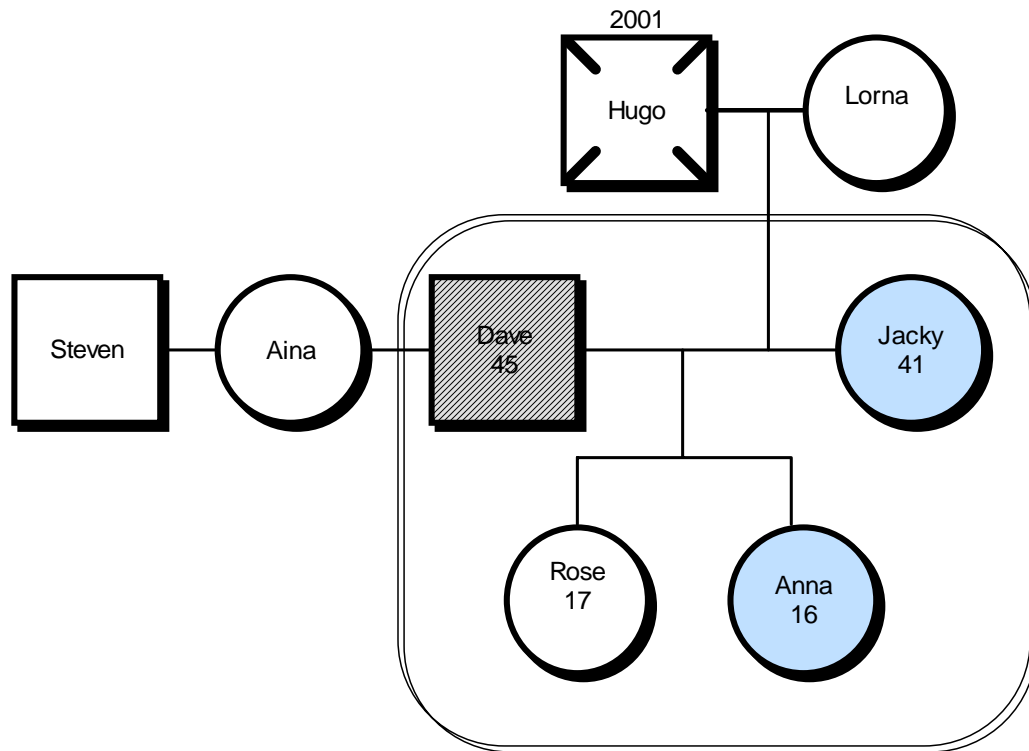
This family seemed to communicate their thoughts and feelings in an open and reflective manner. There were however three different coping patterns observable. Shona coped best when she 'can look up things'. Linda needed to be allowed to ask questions in order to understand what was going on and what was going to happen. Andrew, in contrast, stood back and observed. He was more of the view 'that one can be too involved and you have to trust them to do the right thing.' Getting information was a key coping activity in this family for all three members. Family members said that they used information resources such as the Internet and medical research articles about brain injuries as well as discussions with health care professionals and with each other.

It appeared that Shona had a special role in the family. Due to her chosen professional field she was a source of information to her parents. Hamish's MRSA infection can serve as an example. One day Andrew was told that Hamish had contracted an MRSA infection and it seemed that the nurse assumed that he knew what this was. He in turn called Linda to let her know. Linda however panicked because she thought this was a flesh-eating bug. In her panic she phoned Shona, who then was able to explain to her parents what this actually meant. While Linda later took up this issue of the infection with a nurse, the immediate reaction was to contact Shona for information and reassurance. Andrew and Linda commented that the health care professionals usually spoke to Shona in 'their own language'. To some extent this sidelined both parents. Similar to Ross in family 2, Shona as an adult child was in a position to give support to her parents as well as receive support from them.

Family 6

Family Composition

Figure 9



Family Context

The family presented itself as a nuclear family, parents Jacky (41) and Dave (45) and their biological children Rose (17) and Anna (16). Both children were still living at home. Rose finished school last year and was employed part-time as a sales assistant in their hometown some 60 miles away from the study location. Anna was in her final year at school as required by law but planned to stay on with the idea of entering tertiary education afterwards. Both adults worked: Jacky as a childminder from home and Dave in a local factory.

Dave was the identified patient, who had suffered a stroke. He had never been seriously sick before and had enjoyed good health up to this incident. Jacky pointed out that Dave had never smoked or drunk and that he used to play football in the local club until recently. Given his good health Dave's illness came out of the blue for the family.

While there were other extended family members supporting this family unit, it became clear during the interview that Jacky, Rose and Anna drew the boundaries around them in pulling together, supporting each other, sharing information and experiences and thus coping with the situation as a family unit.

Family Development

Family members had all enjoyed overall good health and the suddenness of Dave's illness has shocked this family. Jacky wondered aloud about the possibility of 'people as young as Dave' having strokes. She had never heard of it before and was confused. In recalling that 'he still hadn't any sort of paralysis, his legs moved and his feet moved' it became evident that Jacky was looking for, what probably most people associated with typical stroke signs; a manifested hemiplegia. The absence of a hemiplegia or any other sort of paralysis confused her.

At the time of the interview Dave had swallowing and balance problems but Jacky was still in denial. She was actively looking for alternative explanations, for example, linking his tracheostomy with impaired swallowing. The possibility that Dave might have suffered permanent disability was not envisaged by any family member. Consequently, the challenge this family faced related to their acceptance of any emerging disabilities Dave might have suffered.

Reflection on Family

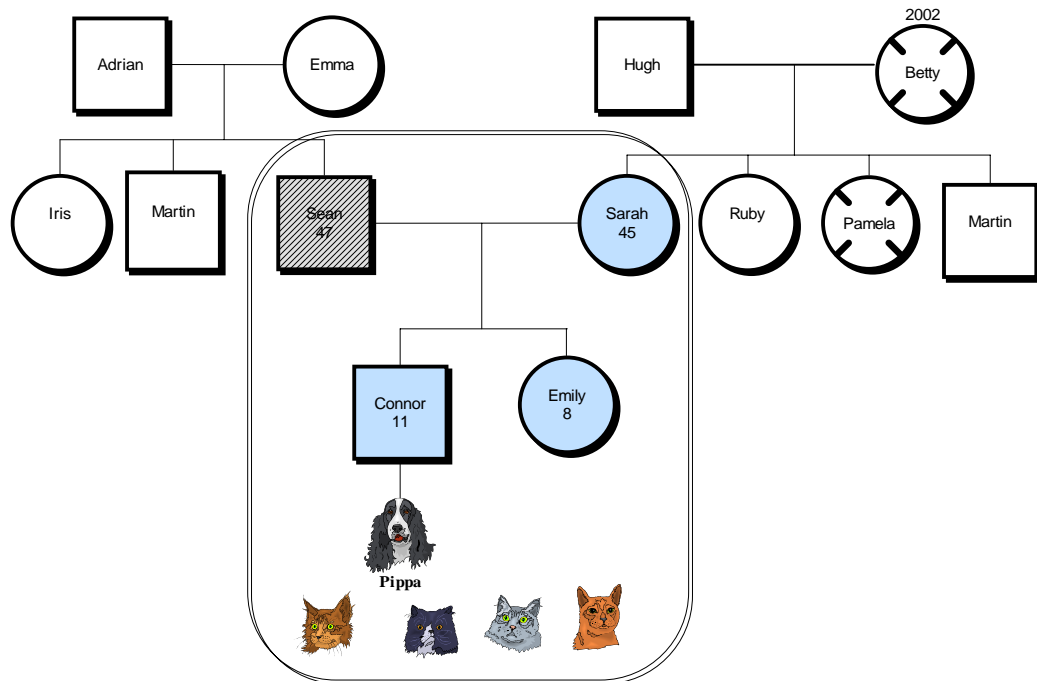
Family members seemed to communicate their thoughts and feelings in an open manner. Both, Rose (17) and Anna (16), were involved in the situation right from the beginning. Two reasons emerged during the interview for this. One related to Jacky's belief that the children had the right to be involved since the situation affected their family, their dad. It was evident that she respected her daughters' agency in letting them decide where, when and at what level they wanted to be involved. Rose, for example, needed some time on her own and she stayed at home at times. Anna, in contrast, needed to be there and be involved. Waiting for Anna to come home from school before following Dave to hospital was one example how Jacky respected their daughters' different needs.

The other reason for involving her daughter fully was Jacky's belief that she 'forgets things awful easy' and that she 'is too stupid' to remember all that was said to her. She wanted the girls 'to be there so that they can back me up and make us remember what they told us.' Forgetting things in a critical illness situation was a phenomenon present across families in this study. Events quite often unfold and move very quickly while the focus of family members remained on the critical ill person and not on a chronology of events. Recalling events in their chronological order was often a family affair in that families co-construct what happened when during the interview. In working together this family supported each other in understanding and retaining information during a time of fast moving events.

Family 7

Family Composition

Figure 10



Family Context

This family consisted of Sean (47) and Sarah (45) and their two children Connor (11) and Emily (8). Sarah worked as a childminder from their home while Sean had just returned to work after a time of unemployment. He worked as a representative for a heating company on a 'earn by sales' basis. Consequently Sean's illness had short as well as long term financial implications for the family.

Sean was the identified patient. He had undergone emergency surgery after suffering a perforated ulcer with a beginning peritonitis. Sean's postoperative condition was so critical that his survival was seriously in question for two days. By the time of the interview he had been in ICU for a little over a week and was stable but still ventilated. The health care professionals had just started the process of reducing sedation in order to let Sean wake up.

It was very much Sarah's belief that their children had the right to be included and informed in a family situation like this. She openly discussed issues during the interview in front of the children and asked more than once their views or opinions on issues. This was, as she pointed out, in contrast to other extended family members

who were of the view that ‘children don’t need to be told.’ In particular Sean’s family of origin had a problem with this approach since discussing openly health issues was not common in that family. These differing views led to some tension between family groups but this was not a major concern for Sarah.

Family Development

A prior critical illness experience in this family challenged individuals in their coping: Sarah’s mother had died two years previously on the same unit. Connor was particularly affected by this. He understood that critical illness in combination with ICU meant there was a possibility that his dad might not survive. Meeting Connor’s immediate information needs was by no means an easy task for Sarah since Connor was not openly asking questions.

In addition, the delay in Sean’s treatment had a profound effect on Sarah’s trust. Though she was very clear in separating the ‘misdiagnosis of the doctor in the receiving unit’, which led to Sean’s current suffering and the ‘excellent care and treatment he received on ICU’, she was hesitant to ‘read too much’ into progress Sean had made over the past days. Sarah adopted a ‘wait and see’ attitude for her own protection. It is not unreasonable to suggest that Sarah’s ambiguous feelings about Sean’s progress were picked up by Connor and thus had an effect on his ability to cope. While both children were provided with sufficient information, Connor was the one who needed more support due to the depth of his understanding of what was going on and its possible implications for the family’s future.

Reflection on Family

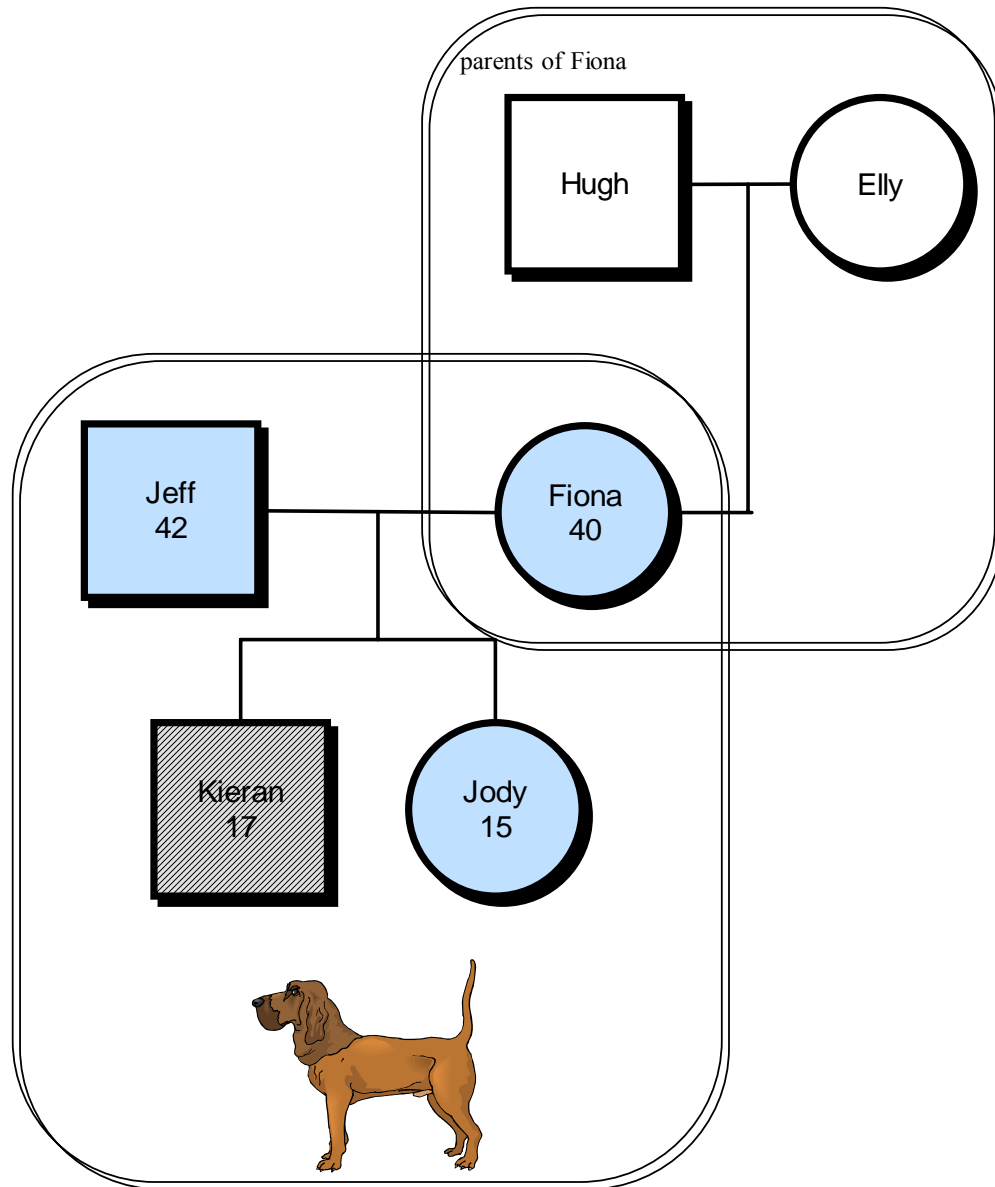
This family seemed to communicate their thoughts and feelings in an open and reflective manner. It became evident during the interview that they were used to discussing family issues together. One example is the meal plan for a week. At one time Sarah faced herself with preparing up to four different dinners each day. Tired of this, she called for a ‘family conference’ to discuss possible solutions. The children came up with the plan to create a ‘meal plan for the week’. This way everyone had an input into what was on the menu and preferences or dislikes were taken into consideration. Up until shortly before Sean’s illness this plan had worked fairly well with all but Sean sticking to the plan.

‘Working together’ was a recurrent theme in this family. Sarah described her relationship with Sean as ‘being a team’. The children took up this team approach (see meal plan). Connor in particular tried to support his mother, for example by doing household chores as much as he could. Emily, reflecting her age, had a more carefree approach to life. The team approach was also emphasised in Sarah arguing that she would take on the role as breadwinner for the family again during Sean’s recuperation period.

Family 8

Family Composition

Figure 11



Family Context

The family consisted of Jeff (42), Fiona (40), Kieran (17) and Jody (15) and presented itself as a nuclear family. The family's home was a two-hour drive away from the study location. Jeff was an electrical engineer with a large Scottish company, while

Fiona was a nurse working part-time. Both children lived at home. Jody, their youngest child, was still at school, while Kieran had just started work in a car company. The family had one dog that was cared for by Fiona's parents.

Kieran (17), the identified patient, had been involved in a road traffic accident and had suffered severe head injuries, a pneumothorax and other multiple fractures. At the time of the accident a friend, James, was with him. James had suffered a concussion as a result of the accident but was otherwise unharmed. Jeff and Fiona's knowledge about the accident was based on what the police were able to tell them. It was for this reason that they knew of a time span between the accident happening and help arriving. This time lapse was of particular importance since Jeff and Fiona knew that Kieran had suffered hypoxia. Kieran's oxygen saturation levels were around 50 % when they arrived at the accident scene. Feelings of uncertainty about the extent of Kieran's sustained brain damage were major issues around which the interview developed. At the time of the interview Kieran had been in ICU for 10 days.

Family Development

The family had accepted on a cognitive level that Kieran had suffered some brain damage. The reactions to an emerging caring situation however differed considerably between family members. While Jody remained more in the background, Jeff was already making plans for the future and Fiona stayed in the 'here and now'. This reaction indicated to some extent the required changes needed, and their reluctance to admit them, by individual family members.

Reflection on Family

Family communication appeared to be very open during the interview. However, I also had the opportunity to see Jeff without Fiona on two different occasions and on both occasions Jeff either expressed concerns about the impact of the situation on Fiona or was critical of medical decisions and actions taken. In not voicing his concerns in Fiona's presence I had the impression that Jeff actively tried to protect her from even more pressure and stress than she already experienced.

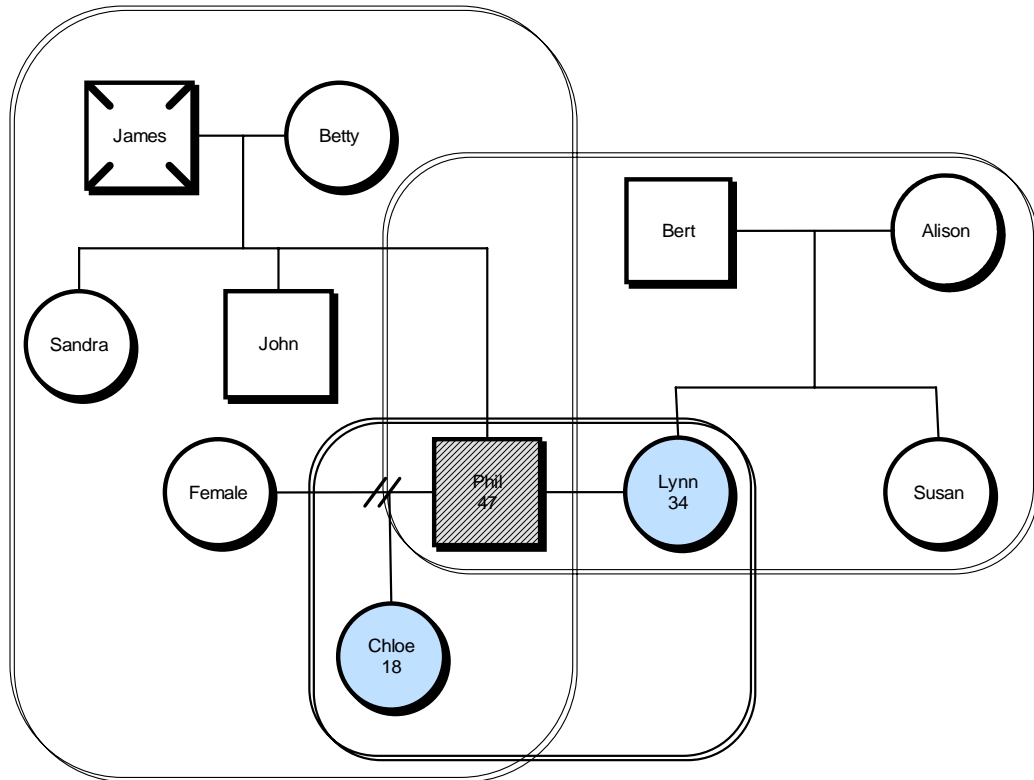
Jeff's separability was visually evident during the interview. He was the one family member sitting on a chair by himself while Fiona and Jody were sitting on a sofa together. Jeff was very much in charge, he was the family member contemplating the future while for Fiona 'life had stopped' and consequently she remained in the 'here and now' situation, taking 'one day at a time'. Jeff was clearly moving on, thinking about securing the family financially and thus returning to work. In fact, for him it was already clear that Fiona needed to give up work in order to care for Kieran. This, however, emerged during the interview and had not been discussed prior to it. That this was a pragmatic choice became evident when salaries were compared, which was the reason why Fiona did not disagree with his assessment.

Jody was included in the experience to some extent. It was, for example, her decision to visit Kieran in ICU. Before going, Fiona used her nursing and medical knowledge to prepare Jody for her first visit explaining in detail what things were and what they meant. The nurse caring for Kieran also helped explain things to Jody.

Family 9

Family Composition

Figure 12



Family Context

Phil (47) was a health care professional while Lynn (34) was a social care worker. The couple had been married for over 5 years. Chloe (18) was Phil's daughter from a previous common law relationship. At the time of the interview Chloe was attending college and lived with her mother near Phil and Lynn's hometown.

Phil was the identified patient. Phil's family had a history of heart disease. His father died 20 years previously of a heart attack while his brother survived a heart attack some 2 years ago. Lynn's immediate thinking at the time reflected this family disease pattern. It emerged however afterwards that Phil had suffered a brain haemorrhage.

As is evident from the Genogram, there are three distinct family units. As mentioned in the introduction to this chapter I called this phenomenon 'families-within-family'. I understood that the emergence of distinctive family units in this family was based on a family conflict in the background. It appeared, for example, that in particular Betty, Phil's mother, was challenging in terms of her behaviour towards nurses as well as other family members belonging to other family units. Betty was reported to have very

rigid ideas about critical illness and her mistrust challenged family members as well as nurses. Lynn was torn by her determination to excuse and understand her mother-in-law behaviour 'for Phil's sake', while Chloe expressed a more critical view of her 'selfish Gran.' The research unit consisted of Phil, Lynn and Chloe.

Family Development

The family conflict in the background was an important issue which involved setting boundaries around certain family members. It is in particular Phil who needs to say what he wants and would like to happen should a similar situation arise in the future. This would help Lynn set boundaries for Betty and protect herself from undue stress due to Betty's demanding behaviour.

At the time of Phil's haemorrhage Lynn had been home, which essentially saved his life. Linked to the unknown aetiology of Phil's haemorrhage, she experienced some separation anxieties. This was evident during the interview when Lynn asked herself 'what if she hadn't been home' questions. In the long term, separations cannot be avoided since Phil and Lynn's work lives involves shift work.

The negotiation of boundaries was not only important for the families involved but also from a nursing perspective. In this case nurses realised the difficulties and tensions these families were experiencing and offered to help. Chloe and Lynn praised the nurses for their insights but felt that they could or should do nothing in order to keep the peace. Nurses hold power over visitors in terms of who can or cannot visit and when. One possible nursing intervention could have been the negotiation of a 'visitor hierarchy', thus protecting Lynn and Chloe's needs while at the same time allowing other close family members to fulfil their needs to see and be with Phil.

Reflection on Family

Focusing on the research family unit it appeared that Lynn and Chloe communicated their feelings and thoughts well. It was evident throughout the interview that they were close and respected each other. Lynn involved Chloe right from the beginning of the illness. It became evident that both supported each other in a mutual and reciprocal way during their experience.

With regards to other family units within this family open communication appeared to be lacking. This might have contributed to a situation in which Lynn in particular was suffering a great deal. The ability of individual family members to cope seemed to be influenced and dominated by the family conflict in the background.

CHAPTER 6

Clinical and functional uncertainty: Families' Experiences during a Critical Illness

Introduction

Clinical and functional uncertainty emerged as a major theme of families' experiences during a critical illness. In this chapter I present the findings relating to this overarching core theme. Quotations from family members and nurses are used throughout the three following chapters not only to elucidate family members' experiences with critical illness but also to demonstrate links between nurses' perceptions of families in ICU and families' experiences in ICU. Explanations of medical terms and abbreviations are provided in the Glossary, while transcript symbols are explained in Appendix 7.

Family or group interviews differ from individual interviews in that interaction is at the centre of data analysis (Kitzinger 1994, Webb and Kevern 2001). Consequently, data extracts are reported predominantly as interactions. Family participants are referred to by their given pseudonyms (see Chapter 5) while the initial 'SK' is used for the interviewer. Nurses are identified by their grade and assigned number. Gender neutral references (as in: the nurse) are used in those focus groups with participating male nurses. This more distant and neutral way of reference was necessary to protect nurses' anonymity: it does not reflect my relationship with any participant or participating group in this study.

A word on uncertainty

In listening to families I realised early on in my study that uncertainty is a major experience during critical illness. Uncertainty during illness is not a new concept in nursing or for nurses. In fact, Merle Mishel's middle range theory of *Uncertainty in Illness* (Mishel 1988, 1990, 1997) has been prominent in nursing research for many years. Barron (2000) points out that Mishel's uncertainty theory, addressing acute and chronic illness, still remains the only nursing theory specifically addressing uncertainty

in illness. Mishel's (1988) original theory draws heavily on Lazarus and Folkman's (1984) work on stress and coping. While she later also incorporated Chaos Theory in her re-conceptualisation of her theory (Mishel 1990), her focus on the illness experience of individual adults remained unchanged. In probing for uncertainty in subsequent interviews it became evident that families talked about a different kind of uncertainty as it was understood and defined by Mishel. It was at this point that the work of medical sociologists like Fred Davis, Jim McIntosh and Renée Fox was helpful in forming an understanding of uncertainty as it was present in my data. Hence, our departure points and end products are very different. In addition, the focus of the following analysis is firmly based on the family as unit. This is a different perspective to the one Mishel is offering, and therefore her work is recognised here but not referenced in my work.

In this chapter I explore families' experiences of clinical and functional uncertainty during critical illness. Some issues raised in this chapter are addressed in more than one section or are developed further in later chapters. The interviews took place at a time where the ill family member was either still in ICU or just transferred to HDU. Sensitivity was needed on my part to respect families' emotional turmoil during this time but also their need to tell their stories.

Critical illness, families and the emergence of uncertainty

The sudden and unexpected admission of a family member to an ICU had a profound and immediate impact on the family. Families emphasized in interviews that roles and responsibilities had shifted to the remaining healthy adult and daily family routines (e.g. meals, getting up routines and so on) were disrupted. One of the first things adult family members needed to organise in response to the ICU admission was time off work, and in some families, care for school age children. Life, as it had been prior to the critical illness, had changed suddenly and significantly for all family members. The seriousness of the situation was underlined by the fact that all admissions in this study were emergency admissions. Consequently, there was no time for individuals to even contemplate the need for intensive care treatment. With the admission of a family member to ICU participating families went through a time of emotional

upheaval and uncertainty - as is also reported in previous research (e.g. Jamerson et al. 1996, Hupcey and Penrod 2000, VanHorn and Tesh 2000, Hughes et al. 2005).

A case in point is family 4. Susan, Jon's mother, described the emotional impact following an ICU admission. Jon (19) had suffered a severe head injury following a road traffic accident. In recalling her experience Susan commented on seeing her son for the first time in ICU:

And to be fair- I've got to say, we were not prepared for what we saw but I don't think anybody could have prepared us. They could have sat down with us for an hour (.3) and tried to describe and explain. Nothing! (.3) I, I just remember being just completely (.5) overwhelmed and shocked and distraught. But I think shock sets in and, and it was like a safety mechanism as well, you know. (.3) You just have to pull yourself together.

[]

I don't know, but I've always kept it in the back of my mind that the staff had enough to cope with, you know, looking after Jon without coping with a hysterical mother who gets herself in such a state that she ends up needing medical attention, so. (.5) It was a huge shock but then I said – I think you're so in shock that all you can do is just sort of sit and stare.

[]

You know and I remember wanting to speak to him (.4) and I couldn't. And (.5) I said to you (*towards Clive, her partner*⁵) that (.4) I realised what the term 'paralysed with fear' means now.

Her emotions of being 'overwhelmed and shocked and distraught' at seeing her son in such a critical condition are apparent here. This family's life was turned upside down when Susan received a phone call saying that he had been admitted to the local ICU. Susan and Clive, her partner, made their way to the local hospital in order to find out what had happened. Sometime around this time Susan informed Jim, Jon's biological father (see Chapter 5), of the accident. When it became evident that Jon needed to be transferred to the study hospital due to the severity of his head injury, it was on Clive's suggestion that Susan and Jim accompanied Jon while he stayed behind to look after the younger children. Jim and Susan saw their son for the first time after the accident in ICU in the study hospital. Jon, an otherwise healthy young adult, was lying

⁵ Throughout the thesis text in brackets and italics within passages of reported speech is used for my own explanatory comments

critically ill in front of his parents, ventilated and unable to respond, with surrounding staff occupied with connecting monitoring equipment. The attending physician knelt down next to Susan, who was sitting on a chair by that time, to explain what was going on and why things needed to be done. Susan's account reveals the shock many family members experienced when seeing their family member for the first time in ICU after an emergency admission. In seeing Jon within the ICU environment, Susan realised that his survival was 'in question'. At this point, issues relating to a recovery from his substantive brain injury and its possible extent were surrounded by clinical uncertainty. She was, in her own words, 'paralysed with fear' unable to speak or 'take in any explanations' given by health care professionals at that moment.

Family members spoke of their 'shock' and 'disbelief' at the onset of critical illness. Beth (family 2), for instance, commented that her husband Brian's admission was 'coming out of the blue'. Ewan (15) and Pam (family 1) were feeling 'devastated' after Graham's ICU admission. Jacky (family 6) expressed her disbelief and shock that someone as young as her husband Dave (45) could have suffered a stroke. Fiona (family 8), Kieran's (17) mother, described her experience following his head injury as 'life has stopped'. Feelings of confusion, fear and shock were reported by families at the time when an ICU admission was imminent or had taken place in order to safeguard a loved one's life. Family members interpreted the need for intensive care treatment as a potential threat to the patient's life.

In the context of the described emotional responses at the onset of critical illness and its subsequent ICU admission the notion of a 'traumatic event' seems fitting. Figley (1998) defines a traumatic event as an experience that is outside the range of everyday human experience and which would be clearly distressing to most of us. The onset of critical illness and its threat to the life of the patient which necessitates an ICU admission is such an event. The Oxford Concise Dictionary (1995) describes the word 'trauma' as indicative of an emotional shock that followed a stressful event. Stress, and here in particular family stress, is therefore the other concept of interest.

Boss (2002a) speaks of family stress as a 'pressure on the family' indicating a change in the family's equilibrium. This, in itself, is not necessarily a negative experience. She points out that:

[t]he family's perception of an event is important in explaining why, given the same event, some families can manage the resulting stress, whereas the event causes a crisis for other families.' (Boss 2002 a:59)

Hence, it is the perception or constructed meaning a family assigns to a stressful event that influences the path taken. It is this notion of constructed meaning that accounts for differences in reactions to a traumatic event across and within families. The potential for a developing crisis in the family or the development of a post-traumatic stress disorder (PTSD) in family members is certainly present. Nurses were well aware of these long-term effects and argued that

S1: Unfortunately. And I think we all feel that post ICU care for patients and relatives is sadly neglected. In - well that's my personal feeling. (*group agreement: mhms*) I don't think we, we do enough to follow these patients and relatives up because it's a post traumatic stress! You know, all the literature, all the evidence says, you know, for patients ICU can be considered trauma and stress and yet there is not the conventional post traumatic stress counselling for these patients and their families out there. []

S3: /Ideally, there should be follow up/

This comment echoes the result of a study by Jones and colleagues (2004) which found that high anxiety levels in ICU patients correlated with high rates of PTSD-related symptoms in their relatives even six months after discharge from ICU. Yet, there is little support for patients or families post-ICU. Equally, not all people who are exposed to a traumatic event develop PTSD or end up in a crisis situation (Rose 1995, Hull and Cuthbertson 2005). Some families demonstrate growth as an outcome of a life crisis, including illness (Hoehn-Anderson 1998, Schaefer and Moos 1998). Hull and Cuthbertson (2005) point out that two-thirds of people experiencing a traumatic event display a normal acute response, such as fear, helplessness, denial, anger, sleep problems and so on, to that event. These emotional responses correlate with those reported by family members in the present study. In the context of families' experiences in ICU it is important to recognise that 'just as in novels and the movies,

trauma seldom affects the individual alone' (Matsakis 2004) but has a systemic impact on the family as a unit.

Boss (2002a) argues that family stress is apparent when even one member of a family shows symptoms of dissatisfaction or difficulties in coping. Implied in this assumption is a systems view of families in assuming that a change in one part of the system has an effect on other parts of the system (see Chapter 3) and this perception of the family as system is particularly helpful in understanding my data. A systems-based conceptualisation of family also draws attention to the relational aspects within families. Here, 'relational', means that people are viewed as contextual beings that live in relation with each other (i.e. family members) and their social world (Alanen 2001a, Thayer-Bacon 2003, Hartrick-Doane and Varcoe 2005). A data analysis that is attentive to relational dimensions in families allows for power as well as gender differences to be acknowledged in understanding families' experiences during critical illness. The power aspect is of interest when analysing young people's experiences in the context of family and critical illness and is further developed in Chapter 7. Gender is also an issue in families where a long-term care scenario was developing and is addressed later in this chapter.

In relation to this study, the topic of 'managing the resulting stress and clinical uncertainty from an unexpected critical illness' refers to strategies family members used to deal with an otherwise ambiguous and clinically uncertain situation.

In response to the onset of critical illness and its high level of uncertainty an immediate need for information was expressed across families. Seeking and getting information is linked to the family's ability to cope with and manage uncertainty. Susan illustrated this point well by talking of her need 'to speak to him.' Ross (25), Brian's son (family 2) argued in a similar way saying that 'being able to talk to them (*ICU patients*) seems to take some of the stress and frustration away.' Had there been the choice, many family members would have preferred to talk to the patient rather than getting the information from health care professionals. Intensive care patients however are often ventilated and in this study all patients were. Hence, any direct communication with the patient was pre-empted due to the patient's need of ventilation and sedation. With

no opportunity of a direct communication, families reverted to observing the patient in the ICU environment. In observing their ill family member, families spoke of looking for clues from the patients themselves to elicit understanding and thus manage uncertainty.

It was of interest to note that families constructed from their observation the meaning and purpose of an intensive care unit. Intensive care is defined by the Audit Commission (1999a:11) as ‘the highest level of care which patients need when two or more of the body’s vital life processes fail’. Families were most likely unaware of this definition, yet they did understand the population intensive care was aimed at. Beth (family 2), for instance, pointed out that ‘only patients who are really, really seriously ill go to intensive care’. Sarah (family 7) talking about Connor (11) and Emily (8), argued in a similar way saying that ‘they kind of understood, you know, you’re in intensive care if you’re actually that sick.’ In particular adults were aware that death was one possible outcome. Young people’s insight to different outcomes rested on their understanding of ICU as function or environment. This analysis is further developed in Chapter 7.

In the context of ICU, Melia (2004) discusses the proper use of intensive care and the ethical dilemma involved in deciding whether an intensive care treatment is in the best interest of a particular patient. Her specific discussion evolves around the ethical issues of withholding and withdrawing treatment. Critical illness situations are notorious for their underlying high level of clinical uncertainty. Predicting, the prognosis of a critical illness and therefore the potential benefit of intensive care treatment, is extremely difficult as is illustrated in the following example.

Brian (family 2) had collapsed one morning at home in the bathroom. Due to his wife Beth’s quick thinking and the prompt response by the ambulance service, he was admitted shortly after the incident to the nearest A & E unit. This, in effect, saved his life. It emerged that Brian had most likely suffered an ‘arrhythmic heart incident’, which resulted in a number of emergency procedures, including a resuscitation, to safeguard his life. At the time of the interview it was obvious that Brian had suffered some brain damage resulting from hypoxia at some point during his illness experience.

The family was now in a situation where the issue was one of an ambiguous loss and feelings of confusion and ambiguity were evident.

Beth: I wish somebody could say, ahm (.3) that there was some research. I mean, I said to her (*a consultant*) 'is this a new thing? Because you've got all this technology to save people with heart attacks or maybe even drowned or anything.' And they're coming back from the edge, they've been saved. (*laughs*)

Ross: It's not new/

Beth: /The patient dies, the operation was a success but the patient dies./

Ross: /It's not new./

Beth: /What's the point?

What was the point? With the benefit of hindsight this family seems to suggest that in this case all efforts to safeguard Brian's (quality of) life were futile. Brian had not 'come round to any degree' (Beth) and the family was now facing a future caring for a severely brain damaged family member. However, at the onset of his illness such an outcome was not predictable. Ross emphasised the clinical uncertainty present at the time of admission when he recalled that the treating physician:

'kept coming out and asking us all these questions about his quality of life. I think they were slightly mystified by the fact that it happened as well, and they would be really expecting- to think that he would have been having health problems over the years. And that would explain why this had happened.'

Brian had had a myocardial infarct some decades earlier but had not suffered from any long-term health problems. He had indeed made a full recovery. The current incident, as Beth was saying earlier, did come 'out of the blue'. It was for this reason that an opposite scenario, namely Brian's recovery, was equally possible at the beginning of his critical illness.

In the above excerpt Beth raised the issue of advances in medical technology with the implied assumption that their use would result in a positive outcome. In the context of neonates, Anspach comments that 'the newborn intensive care unit stands as a monument to science and technology, a living testament to the vast resources that our society has committed to saving life at its beginning' (Anspach 1997:1). This is not

only the case for neonatal intensive care but for intensive care in general and consequently this view is reflected many times over in the current literature (e.g. Curry 1995, Kean 2001a, Phillips and Barnsteiner 2005, Hass 2005). In pointing out that ‘they are not medically minded’, ‘had never been in ICU before’, ‘were amazed by the technology that keeps him alive’ or ‘don’t know anything about critical illness’ the majority of family members emphasised that they had no specific medical knowledge and that it was difficult for them to distinguish between the purpose of the technology and the expectations and hope the use of this technology triggered. Zussman (1994) makes the point that ‘intensive care’ is actually a place and not a technology. Albeit a place whose purpose it is to manage medical crises with technological support for failing organ systems. Chesla (1996) argues in a similar way in saying that the modern medical technology is directed towards the ‘moment-by-moment’ management of physiological changes and needs of critical ill patients. This notion then implies that the use of technology aims primarily at managing physiological crises and its use is by no means indicative of any outcome. This standpoint is reflected in the fact that survival, as such, is understood as an ICU outcome measure in which advances in pharmacology and technology play a significant role in improved survival rates (Keenan and Dodek 2004). Quality of life following an ICU survival however is an entirely different issue. It is this that is reflected in Beth’s ironical remark when she said that ‘the patient dies, the operation was a success.’ Some family members, for example Jacky and Anna (family 6), were awed at the technology they encountered at the patient’s bedside. Jacky commented in reference to the ventilator that ‘he (*Dave*) would not have survived without it’ and praised those ‘who had invented it.’

The human costs are not always clear at the beginning of an intensive care treatment nor can they be. In reality, it is the patient’s condition that forces a physician to act on what is known at that time (Bosk 1979/ 2003). Clinical uncertainty, as is evident in Brian’s case, does not always allow for prognostic certainty on which, in an ideal world, these decisions should be based. It is for this reason that physicians more often than not admit a patient to ICU rather than withholding treatment from the outset (Zussman 1994, Melia 2004). Brian’s case is testimony to this approach. While death was a possibility adult family members considered, the fact that their family member

was admitted to ICU implied for them the assumption that the patient had a chance of survival at the time of admission. Survival, in this context, referred to the family's inferred understanding that a recovery from the critical illness was possible.

Withdrawing into oneself while observing or distancing was another coping strategy used by some family members. Susan (family 4), for instance, pointed out that the shock was so great that one can only 'sit and stare' trying to understand what was going on at her own pace. In her case, withdrawing into herself and shutting out the ICU environment and therefore the explanations staff were offering functioned as protection from becoming emotionally overwhelmed. Andrew (family 5) argued in a similar way stating that 'all we could do was sit and watch this monitor' while waiting for clues how the situation would develop.

Other family members reacted to the shock and distress caused by seeing their loved one for the first time in ICU by distancing themselves in staying only for a short period of time at the bedside. Shona (family 5) spoke of her distress in seeing her brother for the first time:

Yes, I don't think I realised how serious it was until I came and saw. I'd never seen anybody in intensive care before so I just got quite a shock. So, especially the bolt. I think that was one thing that- the bolt, you know, that they'd drilled into his head and he had blood all sort of down his head and things, and it was just caked in his hair, sort of horrible. Yeh. So (.4) I didn't stay very long with him.

Jacky (family 6) echoed these feelings of distress her family members had expressed during the interview in seeing Dave in ICU explaining that 'we went in and out of the unit a lot 'cause it's right distressing seeing him' and 'as soon as we turned around we was crying'. The strategy of distancing shows some variations across families in relation to time spent at the bedside and frequency. While Shona, for example, went home after first seeing her brother, Jacky and her family went in and out a lot, thus stayed near Dave. These two types of variations were also evident in other families. However, despite the distress family members felt and articulated in interviews, going in and seeing marked the beginning of the process in understanding how serious the situation was. The above data suggest that variation in lengths of time spent at the

bedside and frequency reflects the pacing of individuals in managing the situation. Lazarus and Folkman describe distancing as a cognitive coping strategy to help an individual to 'evade the emotional implications of an event' (Lazarus and Folkman 1984:275).

Nurses across focus groups were cognisant of the shock and distress family members experienced in first seeing their loved one in ICU and its implication on retaining information. The following excerpt underlines this awareness.

D3: We're the first line of contact really but pretty much bring it down to not laymen's terms but understanding terms. [] And often when – they're sort of 'rabbit in headlights' when they first come (.1) so you have to kind of – every day there's a new question there. (*group agreement: yehs*) We take it at their own pace, so, we just support them really.

SK: What do you mean when you say 'not just lay terms but breaking it down'?

D3: Well, often if someone has been sort of – it's obviously a really difficult time for anyone to deal with and so (.2) to absorb and remember any information sort of- especially if you're giving lots of planned procedures and what we're going to do and things. Lots of time questions come up as soon as they've gone home and they've got a breather and stuff and then they come back the next day: 'oh, I was thinking this' and so. And also if the prognosis isn't so good we have to gently (*soft spoken*) sort of reiterate that things are going to be very hard and they're very poorly. We sort of prepare them maybe for the worst all the time.

The analogy this nurse was using in describing the family's experience on entering the ICU environment for the first time is an interesting one. Like a 'rabbit in headlights' sums up the shock, disorientation, fear, confusion and uncertainty families experienced at this time. Nurses across focus groups realised that information needed to be repeated for families. In giving information nurses focused on pacing the information according to the needs of the family, translating medical language into understandable terms and reiterating information many times during a patient's stay on ICU. Families' need for information is well established through research and ranks persistently high across family needs studies (e.g. Coulter 1989, Curry 1995, Wilkinson 1995, Tilden et al. 1995, Quinn et al. 1996a, Zazpe et al. 1997). As I argued earlier, seeking information was a coping strategy used by families in an attempt to manage clinical uncertainty.

The onset of critical illness and the admission of the patient to an ICU had a profound and immediate impact on the family as unit. The event itself was described by family members as traumatic, which was underlined by their expressed emotional responses on learning about the critical illness. The core experiences of families during a critical illness however evolved around the different aspects of uncertainty. Uncertainty in this context is two-dimensional: firstly, clinical uncertainty and secondly, functional uncertainty. Uncertainties relating to everyday family life, ambiguous loss and mapping the future were consequences of clinical and functional uncertainties. While clinical uncertainty preceded functional uncertainty, both types became entwined in the course of critical illness. It is for this reason that the following section starts with clinical uncertainty.

Clinical uncertainty

One of the first questions families had, after the admission to ICU, related to the diagnosis, prognosis and outcome of their family member's illness. Sometimes uncertainties surrounding diagnosis and at other times uncertainties relating to prognosis were at the forefront of families' concerns. From a family perspective, the function of a diagnosis was reflected in their expectation that it would enable physicians to make a reasonably accurate prognostic statement about the patient's future and thus alleviate feelings of uncertainty. Families soon had to realise the ambiguity surrounding diagnosis and consequently prognosis.

Family 9 can serve as example. Without warning Phil, Lynn's husband, had collapsed one morning in their bedroom. Lynn's first suspicion was a 'heart attack' but this was quickly excluded by paramedics who upon arrival carried out an ECG. Phil was rushed to the local hospital where initial medical examinations suggested a brain related incident. Consequently, Phil had a brain scan. Lynn recalled the clinical uncertainty after this initial brain scan following his transfer to the study hospital.

Lynn: So, he came- we all came through and we were told he was in intensive care. Ahm - No, in fact that's wrong, he came to DNS (*Department of Neuroscience*), he came here first and we spoke to a neurosurgeon and he told us that it was a very serious condition and we wouldn't really find out for another two weeks if he got through it, kind of thing what, what really was going on. And the next few days he got a couple of scans. The first scan/

Chloe (18): /He had an operation when he first came in.

Lynn: What they'd done was stuck a drain in.

SK: To measure the pressure?

Lynn: Yeh. They told us that it was a build up of pressure and there would be a lot of blood in the brain and ah, obviously they had to put a drain in. We thought he was going to just get operated on there and then but they told us they'd just put a drain in the meantime. He had a scan but it didn't show up an aneurysm and then he had another scan in the week, a more extensive scan, you know and it didn't show up an aneurysm either. So, we still don't know what's caused this bleed which is- although, I mean we're glad that it's not an aneurysm but it's just not knowing what's caused this. So (.2) which is quite concerning.

Chloe: Mhmm, yeh.

During the time span necessary for admission, initial diagnostic tests and referral to the study hospital, Phil's consciousness level had continuously dropped. His first brain scan had confirmed that he had suffered a brain haemorrhage of unknown aetiology. When informed about the scan's findings Lynn recalled her emotion of 'being totally shocked'. Chloe, his daughter, reported a similar emotion. It is evident from this excerpt that a high level of clinical uncertainty surrounded the situation. Uncertainty in this context refers to the aetiology of the haemorrhage, Phil's chances of survival and any possible long-term issues i.e. brain damage or possibility of a re-bleeding. The haemorrhage provided an explanation for Phil's deterioration in consciousness level but the diagnosis in itself did not offer an explanation as to its cause. Consequently, physicians or neurosurgeons were not in a position to make any statement other than the fact that bleeding had occurred. As Lynn is pointing out, the attending neurosurgeon considered the situation as 'very serious' and expected this high level of uncertainty to prevail 'for another two weeks' before they could comment on any prospective long-term issues such as expected recovery or possible brain damage. Families expected reassurance and direction from a diagnosis in terms of treatment and recovery prognosis. This however was markedly absent.

Family 6 is another example where a diagnosis was given while the aetiology remained elusive. Dave had suffered a stroke at the age of forty-five. Prior to his

illness, he had enjoyed a healthy and active life. According to Jacky, his wife, he had never smoked or drunk and had never suffered from high blood pressures. In short, while a brain scan revealed that he had suffered a stroke, it failed to explain why this had happened.

Not knowing why something had or is happening can have a profound impact on the quality of families' and patients' lives. Jerlock and colleagues (2005) examined patients' experiences with unexplained chest pain and its effect on their everyday lives, while Carter's (2002a) study addressed chronic unexplained pain in children and the effect that had on the family. In both studies, medical investigations did not reveal any organic causes for the experienced pain. Subsequently, participants were discharged without a diagnosis. Suffering from unexplained chest pain created a situation where feelings of fear, anxiety and uncertainty were evident and patients experienced the pain and uncertainty inherent in this situation as 'life world-destroying' (Jerlock et al. 2005). In the context of chronic unexplained childhood pain Carter (2002a) points to the 'hurt family', emphasising that the pain affected not only the child but also the family as unit. Illness is indeed a family affair.

In the context of unexplained illness symptoms, Nettleton (2006) speaks of an emerging sociology of Medically Unexplained Symptoms (MUS). MUS is characterised by patients' accounts of illness symptoms (e.g. chronic fatigue syndrome, irritable bowel syndrome, repetitive strain injury) for which an organic explanation can not be found. Not surprisingly, 'living with uncertainty' emerged as one major theme within this area.

The relief of receiving a diagnosis, even if it is a serious one, was apparent in families caring for a child with cystic fibrosis (CF). Jan is one example where a mother of a CF child revealed that she felt 'relieved ...to have a name...to say to somebody, he's got cystic fibrosis. I mean, I thought Willie was dying. I could have kissed that doctor' (Whyte 1994:78). The relief Jan was reporting did not refer to the seriousness of the illness but the fact that a prior uncertain illness situation had changed to a certain diagnosed illness. 'Having a name' provides an explanation of observed or experienced symptoms and hence creates expectations that something can be done and

what exactly can be done is in turn influenced by an established diagnosis. Thus uncertainty turns to certainty, indicating a road ahead.

This view is supported by Christakis (1997) who argues that in medicine the statement of a diagnosis has become a central concern of physicians, partly because prognosis and treatment follow as logical consequences from it. Logically, this implies that one function of a diagnosis is concerned with the management of clinical uncertainty. This is an important point since having a diagnosis not only initiates treatment but also leads to presumptions about the clinical course a disease or illness is going to take (Christakis 1997, Carter 2002a) and hence its prognosis. In comparing her mother's diagnosis with breast cancer some years earlier to her brothers' accidental brain injury, Shona (20, family 5) argued exactly this point, namely that her mother:

‘having breast cancer and that was very much- it's very set. It's like doing an operation and then you have radiotherapy this many weeks and then they can tell you that at different stages if it's any worse. With Hamish, it's just – we don't know.’

Here, the clinical course which followed the diagnosis of breast cancer was clear from the beginning. In contrast, the uncertainty that followed Hamish's brain injury was experienced by the family as ‘everything was up in the air’ (Andrew).

It is rather a truism that the certainty of a prognosis is based on diagnostic certainty (Zussman 1994), therefore somewhat resembling a Catch 22 situation. The interdependence of these two concepts is demonstrated in Phil's case. While here the diagnosis is known due to modern technology, the cause of his haemorrhage remains elusive. A prognostic statement could not be made precisely because this part of the diagnosis was unknown. Yet, the family's need for a diagnosis and prognosis was a request for certainty during uncertain times, a need to know what to expect in and of the future. In this light, it is understandable that families experiencing critical illness appealed for early and direct communication and for honesty about a poor prognosis as soon as possible in order for them to manage uncertainty and prepare for what might be coming (Tilden et al. 1995). Lynn's remark that an earlier scan ‘didn't show up an aneurysm’ and that ‘they still don't know what caused the bleed’ despite an additional, more extensive, scan underlines her need for certainty. This example emphasises the

lingering clinical uncertainty some families experienced due to ambiguity surrounding diagnosis and/ or prognosis where the aetiology of an illness remained unknown.

A further point that can be extracted from the above excerpt refers to Lynn's ambiguity in reference to her relief that an aneurysm was excluded as cause while at the same time the fact that 'just not knowing what caused this' was worrying her. As a result, despite having a diagnosis, the missing aetiology did not offer the family any respite from uncertainty. It was not surprising that the possibility of a re-bleeding, however remote, were stark and frightening. Lynn was only too aware that Phil had survived because she was home when the incident happened. The prospect of sustained uncertainty and more importantly its impact became apparent when she spoke of the future.

SK: Is that the concern that you've got for the future?

Lynn: Yeh, it's just the fact that 'what if I wasn't there?'

SK: Yeh.

Chloe: Mhmm.

Lynn: What could have happened? You know, it's just- I'm so glad I was there, but I just keep thinking about it 'what if I wasn't there?' you know. And it worries me for the future as well, you know.

SK: Mhmm.

Lynn: What if- what if it happens again? But they did say that (.2) there's a low risk of it happening again. He's getting another scan, and MRI scan once he's feeling a wee bit fitter, so hopefully they might be able to find something which would indicate what's happened. But it's been a very, very difficult week. Eh?
(Towards Chloe who is nodding)

It was the prospect of sustained uncertainty associated with an unknown aetiology that challenged this family in moving on. What is emphasised here is not only the clinical uncertainty at the time of critical illness but also the continuation of it for the foreseeable future. While both Chloe and Lynn were reassured by the physician's statement that 'there's a low risk of it happening again', the possibility could not be excluded. The fear of losing Phil was particular evident in Lynn. She questioned

herself repeatedly during the interview ‘what if I had not been home’ or ‘what if it happens again’. The implications of those ‘what if’s’ are of particular interest. There is nothing one can do about the first ‘what if’ scenario. Phil was simply lucky that Lynn was home when the incident occurred. These situations are not subject to influence precisely because they are emergencies characterised by sudden and unexpected onset.

In contrast, the question ‘what if it happens again’ foreshadows the impact a sustained uncertainty might have on the life of this family. Cohen (1995), referring to families experiencing a chronic childhood illness, speaks of ‘heightened uncertainty’. In these families uncertainty was present in a ‘wave-like pattern’, varying between times of intensity and times of respite. A time of heightened uncertainty was triggered by things like routine medical appointments, nighttimes or changes in treatment and so on that prompted a heightened awareness of the chronic illness. More importantly, Cohen (1993) draws attention to the fact that managing sustained uncertainty involves developing strategies to attempt to control the unknown and the unknowable. Watching over someone is such a strategy. In the context of Lynn’s fear of losing Phil, it is reasonable to presume that the unknown aspects of his haemorrhage may result in her watching him for any signs or symptoms of a new bleeding episode. With this kind of background normal fluctuations in one’s well-being for example, headaches or feeling unwell, take on different meanings. Ambiguous symptoms function as triggers to a time of heightened uncertainty (Hilton 1992, Cohen 1995). Watching over someone or ‘family protectiveness’ is a defensive coping response to guard a family against loss and injury (Tapp 1993). Family protectiveness refers to situations where the convalescing patient is awarded a preferential treatment in that at least one other family member is taking on the patient’s responsibilities and chores for the near future (Tapp 1993). In short, the ill family member is closely watched for any illness signs or symptoms. In the long run however this protectiveness can also lead to family conflict. Gillis (1984) as well as Stewart and colleagues (2000) presented data in which heart patients reported an increase in their stress due to overprotective behaviours by spouses. Lynn’s emotional reaction to Phil’s critical illness and the unknown aetiology of the haemorrhage and her tears at different points during the

interview suggest that learning to live with sustained uncertainty is going to be an issue for their future with the consequences for their relationship of ‘watching over’ and ‘being watched over’ undetermined.

The issue of clinical uncertainty was brought to the forefront by Renée Fox⁶, a medical sociologist. Based on her earlier work, she (Fox 2003, 1957, 1959/1998) classified three basic types of clinical uncertainty.

- Uncertainties relating to the imperfect or incomplete mastery of available medical knowledge.
- Uncertainty relating to limitations in current medical knowledge.
- Uncertainties which are connected to the difficulty in distinguishing between personal ignorance or ineptitude and the limitations of current available medical knowledge.

Her seminal paper on ‘*Training for uncertainty*’ (Fox 1957) introduced clinical uncertainty as a feature in the education of medical students. In this, she describes the journey a ‘medical school rookie’ has to go through in the course of his or her training. In essence, medical students are exposed to multiple uncertainties during their training and are required to develop coping strategies for these (Fox 2003).

The concept was further developed in a study, using observation and interviews, on a metabolic research ward (Fox 1959/1998). Here, clinical uncertainty emerged predominantly as a feature of the limitations of current medical knowledge and its implication on treating previously untreatable metabolic conditions. This study is a good example of how medical research in the 1950s was pushing scientific boundaries in order to shed light on formerly little understood hormonal processes. Humour emerged as a protective mechanism for physicians and patients in dealing with clinical uncertainty and its associated stress when treating patients at the cutting edge of medical knowledge. A contemporary example of this kind of research is the Genome

⁶ The terms clinical uncertainty and medical uncertainty are used interchangeably by Fox. I prefer the term clinical uncertainty since it refers to the broader clinical situation.

Project and its potential for future medical application and influence on the treatment of patients.

While Fox argues for the importance and predominance of clinical uncertainty within the education and practice of medicine (Fox 1957, 1959/1998, Fox and Swazey 1979/2002, Fox 2003), Atkinson (1984) criticised her view as ‘too complacent’. He argues that uncertainty has become a taken-for-granted concept, a ‘rag-bag’ for different analytical issues summarised under the heading of ‘uncertainty’ (Atkinson 1984). This echoes a concern expressed earlier by Davis (1966). It is evident in reading the above cited works by Fox, that her research either addressed novice students entering a new academic discipline or medical research at the cutting edge of medical knowledge at the time. These are, by definition, situations in which levels of uncertainty are always high. This is true for professionals as well as for families or patients learning to live with a chronic condition. Carter and colleagues (2002b) provide an example where parental uncertainty in assessing their special needs children’s pain had been replaced by their expertise through learning over time to interpret their child’s reaction, signs and symptoms of and towards pain. In the context of medical students, Atkinson (1984) reasons that training for uncertainty always includes training for certainty. In studying a new subject, for example, uncertainty turns into certainty in the process of acquiring and mastering new knowledge. Learning to make a diagnosis illuminates this process. In focusing on observable patho-physiological signs and symptoms students learn to classify these and eventually assign a diagnosis. This reiterates Christakis’ (1997) argument that the statement of a diagnosis has become a central concern in medicine, hence emphasising the quest for certainty.

Fox’s classification of clinical uncertainty is nevertheless of value in interpreting my data. It is specifically her work on the limitations of current medical knowledge, which is of relevance. In families where the patient had suffered a brain injury current medical knowledge did not allow physicians to reassure families that ‘in the end he will be alright.’ Andrew (family 5), Hamish’s father, emphasised this stance when he said:

‘He (*physician*) said he could give you a thousand different cases- I mean he did say, I can give you a thousand different cases and a thousand different outcomes, you just don't know’.

The outcome uncertainty in cases where the patient had suffered a brain injury is dramatically underlined in this physician's comment. Uncertainty in these cases did not relate to making a diagnosis but the difficulty, if not impossibility, of prognostication. A similar phenomenon was observed by McIntosh (1977) in the context of physicians and their cancer patients in that physicians were able to diagnose the cancer but could not necessarily predict the outcome. Even experience on the part of ICU health care professionals did not enable them to meet families' prognostic information needs to the extent they were looking for. While the diagnosis and location of a brain injury is based on clinical evidence (e.g. scans), prognosticating an outcome is more elusive. Griffiths and colleagues (2005) argue that in applying evidence based knowledge physicians are faced with the dilemma of predicting treatment reactions of individual patients. The above cited comment is testimony to the difficulty of calculating treatment effects. Chalmers (2004) further supports this argument saying that uncertainties about treatment effects are inevitable in medicine.

It is in this sense that families where one member had suffered a brain injury experienced the ‘classical’ form of clinical uncertainty. For the families which participated in this study, current medical knowledge did not support certainty in reference to the patient's outcome. This uncertainty is genuine medical uncertainty or as Davis (1966) calls it ‘real’ uncertainty. In Phil's case, physicians and neurosurgeons found themselves in a situation in which they could state with certainty that a bleed had occurred and pinpoint its location within the brain. Yet, uncertainty prevailed regarding its aetiology and prognosis. The difficulties families had in accepting and living with uncertainty were evident across families and are well illustrated by Lynn's comments.

A second dimension of uncertainty, as identified by Fox (1957), and present in my data might be best described as the physician's personal ignorance of available observational data, which resulted in critical illness as a result of a ‘missed diagnosis’ (Sarah). In the case of this family, Sean (family 7) had fallen ill over a weekend. He

complained about abdominal pain of such intensity that Sarah, his wife, took him to the GP service. The GP, unsure of the pain's origin, referred Sean to a local A&E for further investigation. The attending physician was of the view that Sean was suffering from kidney stones. Sarah had pointed out to this physician that 'he's got no history of having kidney stones. He's got a history of having a bad stomach but not a kidney stone.' However, after prescribing some pain medication the family was sent home. On Sunday, Sean was in such poor condition that Sarah drove him back to A&E. Sean was diagnosed with a perforated gastric ulcer and a beginning peritonitis and underwent immediate emergency surgery.

It emerged that the initial prognosis for Sean's survival had not been good. Before contacting the family one of the nurses caring for Sean said to me 'he really has turned the corner in the last 24 hours. We didn't expect him to.' At the time of the interview Sean had made some progress towards recovery but was still ventilated.

Given the circumstances it was not surprising that Sarah's anger at Sean's critical illness was tangible at different points during the interview.

Sarah: [] And the other thing is, they missed I think a very fundamental diagnosis that he was in shock. (.2) And that- and, you know, I look at him in ICU and I think: 'you don't have to be here.' And it's not fair because the ICU staff have done masses but they have been left to pick up the pieces of somebody else's incompetence.

It is evident in this excerpt that Sarah placed the blame firmly on this individual on-call physician. In fact, she commented later that 'the minute he went up to ICU and the anaesthetist came along to do stuff before the theatre, it changed dramatically. And I'm very clear that from that minute everything has been as I would have hoped it would be.' While this is an extreme case, it is of interest because here clinical uncertainty related to the perceived clinical incompetence of a physician, which had unfortunately serious consequences for Sean and his family. It is essential to acknowledge that during the interview I was in no position to comment on the competence of this physician nor would it have been appropriate to do so. In principle, however, it is reasonable to recognise and accept that there are some less competent individuals amongst health care professionals.

In the above example, the possibility of an error of judgement has been raised (Bosk 1979/ 2003). In Sean's case, the situation as it was reported during the interview, suggests that the A & E physician failed to listen to Sarah and take her information of 'stomach problems' seriously in determining a diagnosis and subsequent treatment. In a sense, he did not consider the 'clinical evidence available at the time' (Bosk 1979/ 2003:45). Treatments or medical interventions, despite there being choices, are based on diagnostic certainty. In this case, while having a diagnosis that initiated treatment and led to presumptions about the clinical course of the illness (Christakis 1997), the alleged error of judgement made early on in diagnosis inflicted suffering on the patient and his family.

Clinical uncertainty also emerged in situations where the aetiology, diagnosis or prognosis remained uncertain for the foreseeable future. As a consequence, communication between family members and health care professionals remained sufficiently ambiguous to keep all possibilities open (Komesaroff 2005). This is the conceptual link between clinical and functional uncertainty and the reason why the former preceded the latter and why both types became entwined in the course of critical illness. In the following section data are presented where both, clinical and functional uncertainty, are evident. My analytic focus evolves around the functional aspects of uncertainty and its impact on families' experiences with critical illness.

Functional uncertainty

Functional uncertainty differs from clinical uncertainty in that this aspect of uncertainty focuses on managing a clinically uncertain situation. Clinical uncertainty in the context of this study is understood to refer to the unknown, and sometimes unknowable, aspects of an illness – what Davis (1966) calls 'real' uncertainty. Functional uncertainty, in contrast, is used as a means to manage individuals or groups during an illness situation for one's own functional gain. Functional uncertainty in this study was evident firstly, in interactions between health care professionals and family members and secondly, in interactions within families.

Functional uncertainty in clinical interactions: the nurses' perspective

The previous section dealt with the dilemma of 'not knowing' what the future might bring and the difficulties families have in coping with such an uncertain situation. In an effort to access information in an uncertain health situation, families quite often stayed near their critically ill patient in order to gain some insights either through their own observations or through interactions with health care professionals. Lynn (family 9) explained that 'just being here and just checking out every so often to make sure he is okay' was an important way of coping and staying in touch with a sometimes rapidly changing situation. 'Being there' has been conceptualised in previous studies as the family's wish to be with a critically ill patient out of a natural concern for the patient's well-being (Walters 1995, Lam and Beaulieu 2004). Further, families themselves saw their role in ICU as one of 'protecting' and 'looking out' for the patient who was unable to do so (Hupcey 1999).

It was not surprising that nurses saw 'giving information' as an important part of their role with families. Nurses understood that they were the 'first line of contact' or 'first port of call'.

D&E 1: Generally we're the first port of call for patient information about the patient ahm (.3) I mean that's my role with the family is to give them information about the patient and what's happening day to day with their patient.

D&E 2: I think it's also to interpret what's actually going on and what's actually said by everyone. And it's often a case of pitching it to the level the individual knows 'cause we tend to get to know relatives better than doctors do because if they're in all day, like some of them do stay, you get to know them after a while. And so - interpretation of what's going on and our perception as to where we're going within sort of limited guidelines.

SK: Can you elaborate a little bit? What does 'interpretation' involve?

D&E 2: Explaining what the therapies are the basic ahm, environment that that patient's in. Interpretation of what the doctors say on ward rounds. (.2) Just a general recapping of what's happening. And often once they're told something once it's three or four times before they actually get through to people. Especially if you've got a big family because some of them get told, and then others who come in here are not told, and they got it from the family who picked it up wrong. (*group: mhms*) So, it's correcting of what was said and trying to go down one channel all the time and just keep someone on the right path while believing something that's been said to be something when it's something else.

There are a number of points that can be extracted from this interaction, one of which refers to emotional labour in working with families, while another touches on the negotiated order between professions. This particular analysis is further developed in Chapter 8. My focus here remains on the different aspects of functional uncertainty that are apparent in this excerpt.

It was evident across focus group discussions that ‘giving information’ aimed at supporting families during critical illness. By the very nature of nursing, nurses are the group of health care professionals who have the most contact with patient and families. This is one of the reasons why nurses are often defined as a major resource for families in ICU (e.g. Leske 1992, Twibell 1998, VanHorn and Tesh 2000) and this perception of nurses was also prevalent in this study. ‘Giving information’ involves not only ‘pitching it to a level the individual knows’ or ‘breaking it down to layman’s terms’ as nurses across focus groups explained but also interpreting the meaning of what physicians think and say about the patient. It involves talking about ‘our perception where things are going’ in order ‘to keep someone on the right path’ in interpreting and understanding the current situation and trying to preserve communication channels with a family or family members. Given the clinical uncertainty inherent in a critical illness, this is an important point. Nurses spoke frequently of ‘gently reiterating the seriousness of the situation’ while families commented that health care professionals did ‘not want you to get your hopes up too much in case it turns out the other way.’ The functions of communication as they are evident in the above excerpt are twofold. While one aspect refers to the translation of medical terms into understandable language, the other feature relates to nurses guiding the construction of meaning of the situation. This is apparent when nurses referred to ‘our perception where this is going’ and in ‘gently reiterating the seriousness of the situation’.

It is in the context of guided communications that the notion of functional uncertainty is of interest. The term ‘functional uncertainty’ was introduced by Fred Davis (1963/1991, 1966). His investigation focused on families where one child had been diagnosed with spinal paralytic poliomyelitis and their experiences during

hospitalisation. It became evident during the course of the disease that families, in this case parents and the patient, did not receive all available information. A distinction between 'real' or clinical uncertainty and functional uncertainty followed this insight. Real uncertainty is the equivalent of clinical uncertainty described in the previous section. Functional uncertainty however deals with the communication routines between physicians and patients or families and its functional gain for health care professionals.

Davis has a fourfold schema: open communication, dissimulation, evasion and the admission of uncertainty. Evasion and admission of uncertainty are of particular interest here. He suggests that in cases where the diagnosis or prognosis is uncertain, two scenarios emerge. The physician will either share his or her uncertainty with the family or patient or withhold information, using strategies of delay or partial disclosure of information. Withholding information, Davis argues (1963/1991, 1966), is done for the functional gain of the physician. One reason relates to the unpleasantness of breaking bad news, for example telling parents that their child is permanently disabled. In a way, not disclosing information and therefore the absence of any confirmation or negative information functions by maintaining hope (Davis 1966, McIntosh 1976).

A further reason, Davis (1966) points to, is linked to the emotional work required in informing and comforting family members after receiving bad news. Withholding information spared health care professionals from dealing with emotional patients or family members.

In the context of this study, guided communications were sufficiently ambiguous to either allow for different outcomes or prepare a family for a likely intervention.

F1: I find that if you- you know, we do tracheotomies and things, and particularly with neuro patients I find that if you are talking to relatives and you know yourself you've got a gut feeling that in the next 3-4 days there's no way they're going to be extubated, their conscious level is not good enough I find that if you slip in things like, you know, ahm, possibly, you know that- you heard that man down there got a tracheotomy the other day and I mean they might think about something like that, just be very vague about it. I find that if then in 3-4 days time it comes to something like that and somebody goes to speak to the relatives they go: 'that's right, (nurses name) mentioned that the other day.' Do

you know what I mean? And they're much more receptive to stuff like that. So if you sort of try to.

F3: Yeh, I think it's/

F1: /test the water a wee bit./

F2: /your confidence and your knowledge as well./

F1 & F3: Mhmm. That's right, yeh.

F3: It's like dealing with patients who are dying or transplantations, you know. All these things, you know exactly because you've done it before/

F1: /Yeh./

'Slipping in things' but 'being vague' (F1) about the possibility of a certain procedure for a family member functioned to prepare families for a likely intervention. While nurses did not know that, for example, a tracheotomy would happen, their experience allowed for a different assessment and foresight in terms of possible medical interventions than family members were able to make. This communication strategy or routine as McIntosh puts it, functioned as a 'gradual build-up' to a required intervention (McIntosh 1977:50). The functional gains in these situations are linked to the family being 'more receptive' and hence compliant in accepting necessary procedures. Being vague and ambiguous was an important part of this strategy because otherwise families would ask questions if the potential intervention did not occur:

F1: And they're: 'why did that not happen?' You know, I think you have to be very- I don't know if that's right or wrong, but I think you have to be a bit/

Group: /Mhmms./

F1: /sort of- unless you know for definite something is going to happen you have to be sort of sit on the fence a bit.

F3: I think we all make comments like that all the time, we never say something is definitely going to happen because-

F1: No. You never know.

F3: Yeh. But to say: 'oh, things are going well' or- you know.

While giving information and keeping families informed of what was going on was important and underlined the unit's philosophy of 'being honest and open' (D&E 2), communications at times remained sufficiently ambiguous and vague to allow for different outcomes. I infer from this that an important aspect of clinical communications is not to resolve uncertainties but to preserve them for the functional gain of health care professionals and the system within which they work. 'Being vague' is the strategy by which this is done. By preserving a degree of uncertainty, health care professionals maintain flexibility in their approach to treating a critically ill patient, instil hope in family members and help to construct new meanings of the situation (Komesaroff 2005). These then are the functional gains of preserving uncertainty.

McIntosh (1976), investigating interactions between health care professionals on a cancer ward and their patients, comes to a similar conclusion. The situation differs in that staff operated on the assumption that patients did not really want to know their cancer diagnosis and physicians used euphemisms such as 'nasty cells' or 'activity' to describe cancer, thus evading breaking the whole story (McIntosh 1976). In contrast, health care professionals in this study tried to be open and honest about the patient's condition.

It is interesting to note that nurses in McIntosh's study concurred with the physicians' approach of not telling. They argued in line with physicians that patients 'don't want to know' but also that 'the atmosphere in the ward would be worse' (McIntosh 1976:71&73) if a cancer diagnosis were disclosed. The functional gain, and hence the similarity between McIntosh and my own work, relates to preserving flexibility in treating critically ill patients. Both nurses and physicians used the strategy of being ambiguous and vague in their prognostic communications and therefore instilled hope in family members. In addition, the gradual build-up of information allowed for calm communications between health care professionals and families and thus, as a nurse commented, resulted in a 'much nicer unit for it' (F1). In essence, it helped to control the unit's 'atmosphere': a clear functional benefit.

It is evident that in Davis's (1963/1991) and in McIntosh's (1977) study 'withholding information' and thus managing patients or families functioned by distancing staff from patient and families to some degree. In the context of the ICU, distancing families or patients is a coping mechanism that functions to protect nurses from emotional overload (Chesla and Stannard 1997, Hupcey 1998). This strategy includes the avoidance of direct communication when the prognosis is not good, leaving the family or patient in the dark and to find out 'the natural way' (Davis 1963/1991). It is directly related to the emotional work required by health care professionals in ICU and this is further developed in Chapter 8.

Caution has to be exercised in applying the earlier study findings (Davis 1963/1991, McIntosh 1977) to today's health care system. Nowadays, as the expressed philosophy of 'being honest and open' (D&E2) in the study ICU testifies, the situation is different. At the time of the above cited studies health care professionals believed patients should not be told if the prognosis was not favourable. This type of behaviour was part of my own nursing experience during the 1980s and resulted in the loss of the patient's trust when we were found out. A number of changes have taken place since then and the increase in chronic illness (e.g. Yacht et al. 2004, Hack et al. 2005) has resulted in more knowledgeable patients and families. That these patients are part of the ICU remit became evident when one of the nurses commented that:

Particularly oncology/haematology patients that have their parents in and their family in all the time, I know that some nurses find it hard work because they're there all the time. And because of the young person's illness, they've probably have it for a long time, the family are really, really knowledgeable. On certain occasions more than us about their certain drugs and things. And that can be quite challenging sometimes. Ahm, I find that quite difficult sometimes. (F1)

Further, information technology like the Internet plays a significant part in today's health care system. Not surprisingly, the issue was discussed in a number of focus groups.

E3: As well, all sorts of medical information is so readily available on the internet now. You find somebody you talk to if the relative has got something

wrong, the first thing they do is go home and research it. Whereas in the past, people would never have thought of doing that they would just have taken it as gospel. The doctor said this is wrong with me (*someone in the group: Yeh, I know.*) and, you know/

E3: /and just accepted what was being told to them. Whereas now- the generations now coming are, you know, are expected to ask and this is the generation- they're always asking, need to know more.

SK: Do they come and say: 'Oh I've researched this on the internet?'

Group: yeh. Aha (*confirmative, overriding discussion follows*)

E3: Oh, 'I read about this', you know, and 'I read about this.'

E1: () and they bring in all these sheets. Especially if they know that they're going to speak to the doctor. I can remember this one family, I can't remember which doctor it was but they were speaking about this thing and they produced all this stuff they'd downloaded off the Internet. And again it depends on the families. You get somewhat more intelligent families who are able to follow what they read and make some sense out of it. And then you get the sort of not so educated families who/

E4: /which is probably most of them.

E1: /yeh, who take things completely out of context and-

E2: That's definitely what my relative needs and they don't accept any answer, you know and the reason why you are doing it.

Nurses in different focus groups echoed the view expressed above that the Internet was used by families to obtain information. It became apparent in focus groups that this easy access to health care information challenged health care professionals in their communication with family members since they could and would question at times what was proposed. The view expressed by one of the nurses, namely that the 'generations now coming [] - they're always asking, need to know more' was reiterated across focus groups. The Internet has undeniably increased the availability of health care information and there has been a shift in perception from 'patient' to 'health care consumer' (e.g. Department of Health 1997, Bolton 2002, 2005). Today, the focus is on informed choices, implying the right and necessity to be informed. As a result, withholding information as reported in the previously cited earlier studies is no longer acceptable. Consequently, functional uncertainty as it was evident in this

study was more subtle than in the earlier studies and related to prognostication rather than withholding diagnoses.

Functional uncertainty in clinical interactions: the families' perspectives

The presence of clinical uncertainty and its implication on functional uncertainty were particularly evident in cases where a family member had suffered a brain injury. I pointed out at the beginning of this chapter that physicians refrained from making detailed prognostic statements. The notion of a 'routine response' (McIntosh 1977) is of interest here. Routine responses are those responses which avoid a direct and/ or complete disclosure of a diagnosis or prognosis. They are based on typifications of questions, for example, 'what kind of recovery is he going to make?' after a head injury or as McIntosh puts it:

'a particular type of question posed by a patient with a particular type of condition elicited a particular type of response. (McIntosh 1977:58)

Physicians remained vague in answering questions relating to prognosis as was evident across families. Lynn's (family 9) earlier comment, that 'they didn't know what caused the bleed' or Jeff's (family 8) remark pointing out that 'they won't give us a thing. They can't tell' might serve as examples. 'You never know with head injuries' was therefore a standard message from physicians and nurses and was reported across families.

At times clinical uncertainty extended also to the treatment options available. Hamish (19) had suffered a severe brain injury after falling from a considerable height. At the beginning of his critical illness Hamish was rather unstable, putting his survival in question. A main problem was his high intracranial pressure levels⁷ (ICP) which reached peaks of 35 mmHg. Controlling the ICP is important in preserving prospects of a patient's recovery since increased intracranial pressures can lead, for example, to seizures or a haemorrhage resulting in serious brain damage or brain death (Arbour

⁷ ICP pressure is usually referred to as a mean value. Normal ICP values are between 0 – 10 mmHg. An increased ICP has been defined as a pressure over 20 mmHg. Marik, P., Chen, K., Varon, J., Fromm, R. and Sternbach, G. (1999) Management of increased intracranial pressure: a review for clinicians. *Journal of Emergency Medicine*, **17**(4), 711 - 719.

2004). The management and treatment of increased ICP levels is complex and challenging (Marik et al. 1999). The family was phoned because:

Andrew: / the brain pressure went way up and we had a phone call at 8:00 on the Sunday morning and they said, the brain pressure has gone way up, we're taking him to have a scan. And they thought at that time 'was he haemorrhaging?' and they said, they would phone back. But after an hour they hadn't phoned back, so we phoned./

Linda: /I phoned, yes.

Andrew: / To see what was going on. So we went and they said it was okay, but obviously the brain pressure was very high at that time and ahm, so we all went down then pretty quickly. And then we met the consultant who told us that he hadn't responded to the (.2) normal treatment. There seemed to be some confusion about the next step because he (.2) he seemed to indicate that what they were going to do, was to cool his body put this blanket over him and bring his body temperature down to from 37 to 34 (*Degree Celsius*). And gave us the impression that it had hardly ever been done before. Ahm, that it had been done in the USA but they had stopped because it hadn't been successful. But he said one of the reasons he thought was because of blood temperature hadn't been tested but then he seemed to be contradicting later because the nurses seemed to say: 'oh yes we have done it before', but ahm, this seemed to be a thing that/

Linda: /Oh, not really, because what the nurses were saying was, yes we monitor body temperature, we reduce people to hypothermia quite often but it's for things like heart failure./

Shona: /Yeh, yeh.

Linda: / So, it's not brain injuries. And that was- it was an unusual treatment for brain injury, an untested treatment for brain injury. But the nurses were all perfectly at ease with it because they did it a lot for other conditions.

Andrew: It was in the paper we read.

Linda: Yes. It was interesting that in the paper we read yesterday which we weren't suppose to see (*Shona laughs*) the temperature was reduced to 33 and in Hamish's case it was 34.6.

Shona: It went under 34. It went down to 33.

Linda: Yeh, they actually wanted to keep it above 34, so obviously they realised, you know that getting down to 33 was a bit –

Andrew: Well, they brought it down so far and then (.3) the ICP came down so they didn't really ()./

Linda: /it worked.

In this case, the family had private access to specific medical literature through one family member which was used to cope with their specific information needs. In contrast, family members across families revealed that they used the Internet to ‘get information about brain damage’ (Jeff, family 8), hypoxia (Beth, family 2) or other issues of their concern. The example is of interest because a number of points made earlier are apparent in the excerpt. There is the policy of ‘keeping families up to date’ with a changing situation; though in this case, health care professionals failed to phone back with the scan result, thus prolonging the uncertainty and anxiety for the family involved. There is the treatment uncertainty inherent in medicine and the problem of predicting treatment reactions of individual patients (Chalmers 2004, Griffiths et al. 2005). There is evidence of routine responses in that the family was interested in whether nurses had any experience in cooling down patients, independent of illness. And there is evidence of functional uncertainty.

Clinical uncertainty here refers to the ‘admission of uncertainty’ (Davis 1966) and is apparent when Andrew recalled that ‘the consultant told us that he hadn’t responded to the normal treatment. There seemed to be confusion about the next step []’. As I pointed out earlier, the treatment and management of raised ICP values is challenging and complex. The ambiguity in this physician’s language was interpreted by the family that ‘cooling down his body’ was an ‘untested treatment for brain injuries,’ emphasising their understanding that the treatment was more of an experimental nature. The physician skilfully maintained uncertainty in being honest that ‘it had been done in the USA but they had stopped because it hadn’t been successful’ while at the same time instilling hope by providing a reason why it might have failed. The function of the ambiguity was twofold. While one aspect related to the gradual build up towards a planned intervention for which the physician needed consent (McIntosh 1977), the other aspect dealt with reassuring the family that they had not run out of options just yet and indicated a treatment path ahead. It is of interest to note that the routine of gradually building up to an intervention is used in a similar way in nursing as it is in medicine. What changes is the content. In my earlier example, the nurse’s

focus was on tracheotomy while here, the focus is on an ‘untested’ treatment. For the family the issue was one of hope. The ambiguity and vagueness in this physician’s language enabled them to find hope in what otherwise looked like a depressing situation. Hope was further instilled by nurses reassuring the family that they ‘monitor blood temperature’ and ‘reduce people to hypothermia quite often’, indicating that this was not an unknown or novel procedure for them. The fact, that it was an unusual treatment for a brain injured patient was omitted. Calm and measured responses by health care professionals often resulted in families commenting that they felt their family member was in ‘safe hands’. This family was no exception.

In the context of Hamish’s situation, it is tempting to think that cooling Hamish’s body down might well have been a desperate attempt to control his ICP level. Had Hamish’s ICP levels remained high the prognostic outlook would have been grave. This however was more implied by stating that ‘he had not responded to normal treatment’ than openly addressed while underlining the importance of managing his ICP levels. Subsequently, it is the paper which according to the family they were ‘not supposed to see’, that draws attention to functional uncertainty. It was these subtle aspects of delaying information about potentially negative outcomes that marked functional uncertainty. In the face of clinical uncertainty, the strategy was clearly one of ‘wait and see’. As one nurse explained it:

‘Whereas, it’s always you’re giving the same school: ‘we don’t know yet, we don’t know yet and we don’t know what brain damage has been done.’ (D&E 3)

In not committing to any outcome and being vague and ambiguous in their communication with families health care professionals left all possibilities open (Komesaroff 2005). This communication strategy by health care professionals was evident across family interviews as well as across focus group discussions with ICU nurses. Andrew summed it up nicely in commenting that ‘all the doctors had said: you never know with brain injuries.’

As indicated above, hope was the other aspect of functional uncertainty that can be extracted from the above excerpt. The positive outcome of the cooling down procedure was by no means clear at the start of the intervention, yet physicians and

nurses alike reassured the family in pointing to their expertise in dealing with cooled down patients. This allowed sufficient functional ambiguity in that a success was never guaranteed but possible.

A number of authors have pointed out that hope and despair are both aspects of uncertainty (Davis 1966, McIntosh 1976, Mishel 1988, 1990). Critical illness accentuates the close relationship of these two aspects. Hope is part of emotion-focused coping and thus an important coping mechanism (Lazarus and Folkman 1984) at times of uncertainty, allowing families to envision a positive future for themselves and their ill family member and hence, hope functions to reduce anxiety levels (Tracy et al. 1999). Similar to the 'need of information', the need 'to feel hope' ranks persistently high in family needs studies (e.g. Leske 1992, Quinn et al. 1996a, Gelling and Prevost 1999). This is a further, more subtle link between communication routines as they are evident in functional uncertainty and the impact they have on families' experiences.

This connection is also evident in situations where despair was the stronger emotion. Hope was nevertheless present, stressing the future orientation of hope and supporting an individual or family to cope by expecting or wishing for a positive outcome (Hunt-Raleigh 2000).

Family 8 can serve as example. Kieran (17) had suffered a very severe head injury in a road traffic accident. In addition, he had suffered hypoxia of an unknown duration which put into question his recovery prospects. The extent of Kieran's recovery was naturally the primary and future focused issue for the family. I had asked whether there were differences in opinion relating to Kieran's recovery prospects.

Jeff: Not really no. They won't give us a thing. They can't tell. They just continually go back to say that he's had a bad head injury and basically that he had two things that were wrong, and the only thing going for him is that he was 17 and he was young.

[]

Fiona: [] I think we've been told a hundred times how bad it is, and I don't need to be told again, you know, I just- (.4) () the neurosurgeon, SHO (*Senior House Officer*) came and he was really nice and just trying to boost us up again. Kind of

trying, don't know, I think they trying and keep us on a certain level, you know, not too down and not too up, and if they see us one way or the other they trying and – []

And Dr D had done a lot of research into head injuries and hypoxia and different things, and he said: 'still at the end of the day it's an individual thing. Some bodies can cope with less oxygen than others.' And 'why' he doesn't know and that's why they can't say what Kieran's is going to be like because they really honestly don't know.

SK: Mhmm.

Fiona: And for us that's all we want to know and nobody can help, so- (.2) we just, we just have to wait and see. (.3) So really, at the end of the day there isn't, there isn't anything what anybody can do. They're saying that they're doing everything that- (.3) [] Because all we want is our son back and (.5) do the best we can do with what we've got.

While the strategy of repeating information is prominent here, the emotions of despair and hope felt by this family in the presence of almost unbearable uncertainty are tangible in this interaction. The communication evolved around the issue that they 'had been told a hundred times' emphasising the seriousness of the situation. In this context it is important to know that this is another family where one family member was a health care professional. Consequently, this family member's understanding and interpretation of the medical information influenced the family's insight of what their future might be. Reiterating information was a routine response by nurses to families in ICU. As I pointed out at the very beginning of this chapter, nurses across focus groups were cognisant of the shock and distress family members experienced in first seeing their loved one in ICU and its implication on retaining information. To ensure that family members understood what was happening, information was repeated. It was however evident in the interview that by constantly reiterating the seriousness of the situation in this family, health care professionals contributed to higher family stress levels, exacerbating the family's suffering. However, the same negative impact of repeating information was not reported by other families.

Jeff's comment that 'they won't give us a thing. They can't tell.' addresses both clinical and functional uncertainty. The admission of clinical uncertainty is evident in the reference to the unknown consequences of hypoxia and any prognostication

relating to recovery. As is emphasised, the reason why some people can cope with less oxygen than other is not well understood. Brain plasticity refers to the ability of the brain to adjust or compensate, at least to some extent, to injury (Springer and Deutsch 1993). While this allows a more positive outlook, it also complicates prognostication and increases clinical uncertainty. It was therefore not surprising that Jeff felt 'they won't give us a thing' since the family was looking for reassurance that they could 'have our son back' (Fiona). Kieran's head injury was so severe, that at the time of the interview, a reasonable prognosis of his recovery could not be made. While the family understood this, they nevertheless needed some certainty in order to plan their own future.

Despite Kieran's rather negative prospects of a possible recovery, physicians nevertheless instilled hope. They reassured the family that they 'are doing everything they can' (Fiona) emphasising Kieran's youth and thus implying his recovery potential. Functionally, in keeping the family 'on a certain level' of coping, the strategy helped to maintain communication channels with the family. This is an important point since family members act as proxy for patients and a working relationship between families and health care professionals is paramount. Once more the functional gain of keeping the family 'receptive' and maintaining flexibility in the care of critically ill patients is evident.

The routine of gradually building up (McIntosh 1977) is also manifest in the above excerpt. Continually reiterating information, in particular if this information was not of a positive nature, functioned by preparing the family step-by-step for a likely outcome. In the case of participating families, this referred specifically to emerging scenarios of long-term care. While this was never said directly, it was implied by stressing the seriousness of the brain injury and the routine response that 'one never knows with head injuries.' Nurses went one step further in their gradual build up to a caring situation in that including families in care activities was seen as important since

D 3: [] say spinal patients that have come in until they go to Glasgow and it's sort of like it's good to get the patient's relatives in as soon as possible because potentially this could be them forever doing this kind of role.

The routine of gradually building up was therefore evident on a psychological as well as practical level. Including families in caring activities as a nursing intervention is further discussed in Chapter 8.

Functional uncertainty was not only evident in communications between health care professionals and family members but also in families themselves.

Functional uncertainty in family interactions

In some families functional uncertainty was evident in their interactions. Similar to the situations described above, strategies of withholding information and evasion (Davis 1966, McIntosh 1977) were used. While the strategies were alike the intentions differed. The objectives of functional uncertainty in families were two-fold and linked: firstly, to protect children from the stresses and strains of critical illness, and secondly, to create some space, time and respite for the parent by providing time for their own coping with the demands of critical illness.

The point at which functional uncertainty becomes relevant differed between families and within this set of families two basic types emerged. First, there is the parent who withholds the critical illness of one parent or prevents children from visiting their ill parent on ICU. The data relating to this type of family are from nurses and their experiences with these families since no family interviews were possible. Second, there are families who include children in the illness experience but use evasion to protect their children from the full force of critical illness. Data relating to this group are from participating families.

In the following section my analytical focus remains on the functional aspects of the strategies of withholding information and evasion. The impact functional uncertainty strategies had on young people or nurses are further developed in Chapter 7 and Chapter 8.

Withholding information

One of the most difficult aspects of this study was data relating to parents who had either chosen not to disclose the critical illness of a parent or who excluded young people from visiting their critically ill parent in ICU. These data, drawn from nurses'

focus groups, are full of emotion and at times, the nurses' despair about not being able to alter the situation for the family and themselves was palpable. Ultimately, parents function as gatekeepers and it is within their power to decide whether to include or exclude children at a time of great upheaval for their family. The repercussions of this decision however were felt within the family system and the nursing system. In focus groups nurses frequently mentioned that parents or grandparents asked for their opinion and advice on whether they should bring the children in. One mother recalled that she 'was told by the consultant that it would be good if she could bring in her daughter (aged 10) to visit daddy.' In this case, the father was suffering from Guillain-Barré Syndrome, a neurological disorder, and required prolonged ventilation. In general, health care professionals understood that critical illness also affected children, those who came to visit and those who had stayed at home. Including children and young people was encouraged by many nurses but it is evident from the literature discussing and criticising the exclusion of children and young people as visitors in ICU that this is a recent phenomenon (e.g. Titler et al. 1991, Craft et al. 1993, Johnstone 1994, Clarke and Harrison 2001). Despite the openness of nurses to children and young people as visitors in this ICU, not all parents chose to bring their children.

At times parents managed to withhold the information that a parent was critically ill and in hospital from their children altogether. In discussions about children as visitors in ICU the following story emerged.

S1: I remember one of my colleagues, who is a mother, came to me very distressed after a night shift and what had happened was, her patient had died overnight () and the father had turned to her and grief-stricken, he grabbed her by the arms and said 'just tell me, how do I break this news to my children? You tell me, how I tell my children of 6 and 4 that their mother is not going to come back?' And she said; 'I lost it at that point. I was just so distressed.' She said: 'I managed to hold it together enough to say to the dad: 'you know, you, you will find the strength. You will find the words, you know, just take some time. And if there's anything we can do to help.' But she felt soo – ahm how did she described it? As helpless in that situation. She said: 'I just didn't feel equipped to help this man you know, to tell – how to go about telling his kids that overnight their mummy had died.'

SK: Mhmm.

S1: And this father had chosen not to tell the kids that the mother was even seriously ill. So, I think he'd said something to the young kids thinking he was sparing them about the mum being on holiday or their mum being visiting a friend when in an actual fact the mum had been with us for a couple of days.

This excerpt is a very powerful example addressing not only aspects of the emotional work of nurses working with families, and in this case with a bereaved family, but also the view of children in our society in terms of their 'need' to be protected from stressful critical illness situations. The emotional labour aspect is further developed in Chapter 8, while Chapter 7 deals with the experiences of young people in relation to critical illness. My focus here remains on functional uncertainty.

'Sparing the children' (S1) and hence protecting young people from the harsh reality of critical illness was the driving motivation for parents. In the above example clinical uncertainty and the unpredictability of critical illness is once more evident. In choosing not to disclose a serious life threatening illness a parent ultimately takes a gamble with the trust of his or her children if things go wrong. Openness and truth is something which is highly valued in our Western culture (van Manen and Levering 1996). Lying, consequently, is not. Yet children, aged between eight and eleven, understood that parents sometimes lie to protect them (van Manen and Levering 1996:153). Despite this insight by young people, in a situation of critical illness the consequences of lying can result in a break-down of trust in a parent at a time where this trust is essential for understanding and coping with either a critical illness or the loss of a parent. The support needed by a child in a situation where adults have problems coping is self-evident.

At other times parents withheld information by postponing a visit to ICU. When asked during focus group discussions why parents chose not to bring in their children, nurses frequently argued that parents thought their children were too young to understand or that the ICU environment was too distressing for them. In particular seeing the sedated, unresponsive patient was deemed too stressful for children by parents. Parents argued that it was better for the children to postpone visits until the time the patient 'was awake again.' This view was in contrast to nurses' experiences. They argued that where a patient's sedation is being reduced this often results in an agitated

or restless patient and is ‘a lot more frightening’ for young people than a quiet, sedated patient. Sarah, Emily’s mother (family 7), supports this observation reporting Emily’s reaction as one of confusion and anxiety to her father’s restlessness at this particular time. This was actually one situation where nurses would ask families ‘not to bring in children’ until the time had passed. Postponing children’s visits to ICU effectively functioned to withhold information, impacting on the ability of children to understand and cope with the situation. In not providing sufficient information young people were left to imagine and try to figure out what has happened on their own. I concur with Lewandowski’s (1992) and Dale and Altschuler’s (2006) insights that these fantasies and imaginations are usually far more upsetting than reality, leading to feelings of being alone, unsupported and isolated at a time where they need their parent’s support and reassurance most.

The views and needs of children and young people with an adult family member in ICU are suspiciously absent within the research literature (Kean 2001a). Only a few studies have actually included young people in their design. These studies reiterate the above presented arguments, namely that children were perceived by adults as too young to understand, the situation was too anxiety provoking or distressing and therefore children needed to be protected from the critical illness and ICU environment (e.g. Titler et al. 1991, Craft et al. 1993, Clarke 2000, Winch 2001). In listening to young people a very different picture emerged over time, seriously questioning the parental assumptions of young people’s need to be ‘protected’ from the experience of critical illness (see Chapter 7).

The distress young people experienced if they were excluded became evident in the following example. This particular family had been discussed in several focus groups, underlining the nurses’ concern regarding the children’s exclusion. In one focus group discussion a nurse explained that the mother had suffered a seizure at home which was witnessed by her children aged eight, nine and thirteen. Diagnostic tests confirmed a brain haemorrhage with an unfavourable prognosis.

D3: [] And the husband, her partner wouldn’t let the kids come in and just kept saying that ‘mummy had a couple of breathing problems and was being looked after.’ And (.3) sort of all the relatives were like ‘Could you try and talk to him

to see if we can bring the kids in? They're really concerned about their mum but they didn't want to right the dad. And when I chatted to him it was a, it was a brick wall, he didn't want them to see what he was seeing. And I think it was his fear and I could understand that. But, what if something happened to her and the last memory they had of their mum was seeing her being rushed off in an ambulance. And, maybe it would have been scary initially to walk in the room and see the ventilator and the monitors and things but once you break it all down and to say: 'well, actually this is all for us it's really that machine that's helping your mum breathe just now, but that's only for a short time. The rest of it's just for us to keep us right.' Because most of the machines are just for our sort of obs (*observations*) and things. I don't think it would have been that scary for them.

Similar to the former example this excerpt has a multitude of interesting dimensions. It underlines the emotional work in supporting parents to include their children but also supporting a family in which a conflict is evident. Here, the nurse described the reaction of the father as 'a brick wall' arguing that 'he didn't want them to see what he was seeing'. This reiterates the earlier argument that children are perceived as being too vulnerable to be exposed to critical illness and the ICU environment. It is equally evident that other family members understood the need of the children to see their mother. 'Going in and seeing' is an important part of coping for younger children who tend to understand ICU on a more concrete level (see Chapter 7). Seeing, and thus being reassured, that their parent is still alive helps young people to cope with critical illness (Titler et al. 1991, Lewandowski 1992, Craft et al. 1993). The strategy this father was employing was one of withholding the seriousness of the situation - which is evident in him saying that 'mummy has a couple of breathing problems' which does not tally with the real issue of brain damage. If the prognosis that this mother had suffered a permanent brain damage becomes reality, then this father has created a very challenging situation for himself and his children by evading the real issue. It should be remembered that parents as well as nurses have the power to shape experiences and memories of young people with regard to critical illness (Lewandowski 1994). Connor's (11, family 7) reaction to his father's critical illness, for example, is testimony to the fact that prior experiences have an influence on a young person's ability to cope with critical illness in the future (see Chapter 7).

In the above excerpt, the nurse interestingly suggests that the father's behaviour was rooted in his own anxieties and fears about the situation. This suggests his understanding that his wife might be permanently brain damaged and that a long-term caring situation was a real possibility. In reassuring the father this nurse tried to support him to recognise his children's need to visit their mother. Distancing his children and telling a protective lie functioned to 'buy time' for him to cope with the situation. Yet, the children's concern is evident in the above excerpt. In having witnessed the medical emergency and with no opportunity to reassure themselves that their mother was still alive, they were left to wonder what was happening. A number of studies describe the benefits of children visiting their ill parent in ICU. Benefits related to an increase in their understanding of what was going on, minimisation of adverse behavioural and emotional responses such as an reduction in anxiety levels but also the fact that children felt included in the family crisis situation (e.g. Lewandowski 1992, Craft et al. 1993, Nicholson et al. 1993, Clarke and Harrison 2001, Knutsson et al. 2004). In preventing children from visiting their critically ill family member, there is the danger that parents' needs may override the needs of their children. In this sense, functional uncertainty indicates a power asymmetry within family systems, underlining the gate keeping function of parents.

On the other hand, the stress and strain of critical illness can be so overwhelming for the healthy parent that they are unable to reassure or respond to the needs of their children (Lewandowski 1992). They simply need some time to come to terms with the situation. It is however the impact of the temporary inability to look beyond one's own needs that defines the functional gain of withholding information and the need of protecting young people from the ICU as a parental gain. In the meantime young people suffer in silence. Further, as is evident in both examples provided, parents did not necessarily consider the consequences that protective strategies might have for their children and the future of the family. Parents are the gatekeepers to their children and even in a situation where other family members or nurses recognise the need of young people, they can not act without parental consent. Consequently, in the above situation nurses had to back off and observe in silence.

Evasion

Some parents included their children in the critical illness experience. Similar to McIntosh's findings relating to physicians' communication routines with patients, parents used certain evasive routines in their interactions with their children. While one of these routines was concerned with responding to questions, the other involved volunteering information (McIntosh 1977). Sometimes these young people had the opportunity to visit their ill family member in ICU and see for themselves what was going on, while at other times they were kept informed of what was happening. 'Seeing for themselves' cannot be equated with understanding what was going on or what the implications were for the patient and the family (see Chapter 7).

A case in point is family 3. Peter had suffered a severe accidental head injury resulting in brain damage. While he was stable at the time of the interview, the outcome was uncertain. Fay (12) and Mona (10), his daughters, had visited him on a number of occasions, yet they had not really understood the severity of his head injury.

Fay (12): Actually mum, what's got dad wrong with him?/

Mona:/ I smashed the clock.

Fay: What's got dad wrong with him?

Mona: Yeh, I want to know that too.

Fay: What has he actually got wrong with him?

Julie (*mother*): We don't really know – he is, he is heavily sedated (.3) well, they're trying to keep his brain quiet.

Clinical uncertainty prevented any precise outcome prognosis. Fay, being older, was more suspicious about her mother's reluctance to answer her questions. She clearly sensed that something was very wrong but lacked the information to understand what it was and what the implications might be. Julie, their mother, however was hesitant to engage in the discussion. She answered only in response to a concrete question rather than volunteering information. Her strategy of evasion was evident when she said that 'we don't really know' and provided an explanation that this is due to the fact that 'they're trying to keep his brain quiet.' In doing so, she did not lie to the girls since

both could confirm her answer because they had seen Peter in ICU and had been informed that he was sedated and why. Julie just did not tell the whole story. In disengaging and distancing herself from the interaction she bought herself some time to deal with the situation herself. This became apparent when asked how she was coping with the situation and she answered 'barely'. Her distancing behaviour can be explained by what Lazarus and Folkman (1984) define as a cognitive coping strategy to help an individual to 'evade the emotional implications of an event.'

In avoiding the whole story and the possibility of a brain damaged father, Julie maintained hope in her children that things would be alright in the end. That the girls were hopeful of a positive outcome became clear when they started discussion of their next family holiday sometime in the future.

The other strategy parents employed related to volunteering information. Family 4 can serve as an example. Jon (19) was the brother of Carrie (18), Alan (13) and Ben (7). He had suffered head injuries in a road traffic accident and had been transferred to the study hospital from a different town. All three siblings were at times cared for by different family members in different households. Susan, their mother, spent long hours with Jon in hospital but made a point of looking for her children in an attempt to keep them informed of the situation.

Susan: I came, I think it was either the Saturday or the Sunday. I came up to your dad's because I wanted to see Alan, I wanted to speak to Alan himself and I tried to explain as much as I could without (.4) scaring him (.3) what the situation was. And we also described to Alan what Jon had, you know, two leads on his head and on a ventilator, and he's got different lines going into him and drips and () and hooked up to monitors./

'Trying to explain' what the situation was without 'scaring him' indicates the selective nature of this strategy. Similar to Julie, Susan did not lie to her children but selected what she revealed. Her information was based in the present and focused on the concrete (e.g. monitors, leads and so on), while omitting any potential prognostic outcome information. In this context, Clive, Susan's partner, commented that they 'did not know what to tell the kids', underlining the impact of clinical uncertainty in

these situations. The same information strategy was used with Ben, the youngest. Both brothers did not visit Jon in ICU. Alan, because he could not bear to see his brother 'like that', and Ben, because Susan thought he was too young to understand.

Carrie and Alan however had serious concerns regarding their brother's head injury. They understood that Jon had potentially suffered long-term brain damage. It emerged in the interview that Alan's anxieties about visiting him in ICU were directly related to this potential outcome. In volunteering information Susan pre-empted questioning. It was interesting to realise that Susan's positive attitude and her belief that 'with the family's support Jon will pull through this' not only maintained hope but also undermined discussion of any other outcome. Again, the functional gain was linked to the parents' benefits in gaining time to cope and deal with a difficult and uncertain illness situation. As a result, Carrie and Alan felt isolated and unsupported (see Chapter 7).

The modes of withholding information and evasion from Davis's (1963/1991, 1966) model are easily identifiable in parental interactions. With regards to critical illness an important difference between withholding information and evasion lies in the fact that the former requires some sort of lying while the latter withholds part of the available information. McIntosh (1977) points out that half-truths can be build up later if the situation requires it. Hence, parents using evasion remained flexible in their approach to including their children. It is feasible that this strategy could be used by parents to gradually prepare children for a future family scenario, for example, an emerging caring situation. In contrast, parents who withheld information of a serious illness or the seriousness of an illness and had used a lie to protect their children were likely to face serious problems when 'things went the other way.'

Through strategies of withholding information and evasion as defined by Davis (1963/1991, 1966) functional uncertainty was maintained in communications between health care professionals and family members but also in interactions between parents and their children. The functional gains differed according to the system. In the case of health care, the functional gains referred to the management of families in keeping communication channels open, instilling hope and maintaining treatment flexibility

and the family's 'receptivity' to suggested interventions. These strategies also ensure a smooth running of the unit. Within the context of families, functional gains were linked to parents. Parents withheld information or evaded questions in an attempt to protect their children from the stresses and strains of critical illness and to buy themselves some time to cope and deal with an uncertain health situation.

It was evident across family interviews that the onset of critical illness and the emergence of clinical and functional uncertainty had an impact on the family's immediate and long-term future.

The communication strategy used is one of ambiguity, attempting to keep all possibilities open for the future. Leaving families or family members with some hope for recovery was the main intention of this strategy.

Uncertainty: impact on families' future

The outcome uncertainties of critical illness challenged families in planning their short and long-term future. Families experienced many changes and disruptions to their daily routines, for example family meals were suspended, communication times were reduced and children were required to stay with friends or relatives. In this respect, my findings correlate with a number of other studies (Titler et al. 1991, Craft et al. 1993, Hupcey and Penrod 2000, VanHorn and Tesh 2000). The flexibility necessary during times of uncertainty made it difficult to plan any activity in advance. Andrew (family 5) summed it up when saying that 'you can't plan ahead.' Future becomes an elusive concept, suspended in time and space.

Work and child care

After the onset of critical illness the immediate short term issues related to getting time off work and organising child care. In this study all adult family members had taken time off work. Family members spoke of their entitlement to compassionate leave but did not necessarily know how 'that is playing out financially' (Jeff) later on. I was somewhat surprised at the level of support employers and work colleagues offered family members by making it easy to get time off work. In some cases employers had not issued a time restriction but had asked to be 'kept informed' of the situation. In

other cases colleagues arranged ‘unofficial’ extended time off periods to allow someone to be near the critically ill patient. This reaction by employers and colleagues suggests their understanding that the situation was exceptional. In general, employers were generous and paid wages as usual.

In the case of self-employment the family member had to work since, as Andrew (family 5) pointed out if ‘you don’t work, you don’t get paid.’ Self-employment includes those families where women worked as childminders from their homes. While Andrew, for example, could adjust his working hours to suit the demands of the situation, child minding women could not. In these cases they had to cancel their child minding sessions thus losing a vital source of income and not being able to earn money needed for living increased the financial burden of critical illness on these families. In addition, particularly for families at a distance from the study hospital’s location, overall living costs had gone up due to travel costs and parking charges. Living costs also increased since families spend prolonged times in hospital and were more likely to buy food in hospital shops and canteens. In one family, colleagues of the patient had collected money in order to help cover this type of cost.

The financial impact of critical illness on a family is a neglected area and only occasionally mentioned in North American Studies (e.g. Johnson et al. 1995, Hupcey and Penrod 2000). Differences in how health care is financed (insurance versus tax) might be an explanation why it is often ignored within the UK context. An exception is a UK study by Thalanany and colleagues (2006) pointing to the same areas of increased spending as I have argued above. The notion that ‘care is free at the point of delivery’ muddies the waters in terms of overall financial impact of a critical illness on families. It became obvious in this study that some families did struggle to make ends meet when a vital source of income was suspended due to critical illness.

Child care was another issue which arose in some families. The need for a parent or parents to stay with the patient resulted for a number of young people in prolonged separations during a time of uncertainty. It is here that the interdependence of families with other social networks became apparent. Hansen (2005) describes this kind of care as ‘not-so-nuclear family’ care in pointing out that not just family members but also

friends or good neighbours, social networks in other words, pull together and participate in caring for school aged children. While her context is the everyday situation of American families across social class and their childcare cover during working hours, it is relevant here since this is the kind of network families fell back on in emergency situations. She goes on to argue that these social networks are largely hidden from researchers, policy makers and the public in general (Hansen 2005:210). The existence of care networks is usually assumed by others, including health care professionals. This was evident in focus groups discussions when nurses discussed those families who had to bring in their children because they lacked childcare. One example related to a mother of two young children, one of which was still breastfed, and her problems of finding childcare cover because, as one nurse pointed out, 'his family does not help.'

In contrast, participating families had access to social or/ and family networks, which were crucial in enabling families to focus on the critically ill. Family 8 is a case in point. Fiona and Jeff stayed with Kieran while Jody (15), his younger sister, was cared for by a family's friend. Knowing that Jody was safe and cared for, allowed Fiona and Jeff to concentrate on Kieran's situation. This does not mean that a prolonged separation was unproblematic. It was not. When asked how the situation was for Jody, she answered:

'Quite hard because I've got to wait before I can find out what has happened.'

Yet, Jody understood why her parents needed to be near Kieran. In other families, varying family members looked after school aged children. Some neighbours provided families with food (e.g. pies or soups) in an effort to alleviate the pressure on the healthy parent. Despite this support, be it from family or others, ultimately the responsibility rested with healthy parents and they had 'to go it alone' (Hupcey and Penrod 2000).

Mapping the future

For some families, specifically those where the patient had suffered a brain injury, a caring scenario emerged during their stay in ICU. Parts of the clinical uncertainty experienced in these families related to the unknown and unknowable aspects of

recovery. As outlined earlier, predicting the extent of recovery in these cases was impossible. This situation left families 'in limbo' (Ross, family 2) as to what their future might be. Certainty existed in the sense that a caring situation was foreseeable. The changes which were required by individual family members in response to the situation remained unknown. Jeff (family 8) underlined this aspect of uncertainty saying that:

'I'll think forward but it's difficult for – (.2). There're all the different scenarios that will come into play, but if one of us has to give up working first, it would be Fiona because I think one of us has to provide for the family that would be a problem.'

The different scenarios Jeff mentioned here refer to contrasting degrees of recovery. These range from the patient's full recovery to a total dependence on care, each of which requires a different response from the family. Mapping a future is about refocusing one's time perspective from the present to the future and thinking about 'how to move on the map' (Charmaz 1991:190). For Jeff, the focus was on providing financially for his family. He revealed during the interview that he had started to think about returning to work 'maybe as early as next week'. While this was after almost two weeks of Kieran's ICU stay, for Jeff, on an individual level, it was time to take the next step 'on the map' and return to some form of normality.

From a family perspective, mapping the future was linked to retaining hope for a good enough recovery, so that a total care dependency did not materialise. It was at this point that the impact of sustained clinical uncertainty after brain injury and its difference in meaning for individual family members became apparent. This is evident when Jeff argued that 'first, it would be Fiona' who would need to give up working in order to meet Kieran's care needs.

Jeff: I think at the end of the day it's easier almost it's easier, but it is easier for myself really because I will have some sort of life no matter how Kieran comes out of it. Again, Fiona for instance, might have to give up her work and look after him, which then becomes more () rest on Fiona then. (.2) I can go back to my work, that's when it starts to become harder if that's what happens.

At the time he said this with such conviction that I probed whether this was an agreed way forward for this family.

SK: Were you discussing-?

Fiona: No!

Jeff: No. (.2) But at the end of the day-

Fiona: My salary is about a tenth of his (*laughs*) So you can't- I mean the practicalities, I mean (.3) you need money. Sad isn't it that it comes down to that? But it's just the way it is.

Jeff had voiced his view for the first time during the interview, testing Fiona's reaction to his position in a situation where her emotional reaction would be contained since I, as an outsider to the family, was present. While Fiona was surprised at Jeff's comment during the interview, her reference to the difference in salaries and the need for money to support the family's life reflected a pragmatic choice in order to secure the family's future. The extent of changes to their individual as well as family lives that families had to face in an emerging caring situation was beginning to show. 'Thinking forward' was particularly difficult for the designated main carer.

Fiona: Mhmm. It's just coping every day instead of trying to look too far ahead.

SK: Because of the uncertainty or because you're frightened of the future because of the uncertainty?

Jeff: Because of the uncertainty.

Fiona: Both of it.

In another family Linda (family 5) offers the following assessment of her future.

'But I mean as the woman in this – and a mother in this family. I have – it had occurred to me that they (*Shona and Andrew*) could carry on with their lives but I can't because of him (*Hamish*). It's going to be me who has to give things up. (.3) And ahm it's one of these things.'

The theme which emerged over time relates to women as carers. Across family interviews and as is evident in both family examples provided here, women were expected to, or expected themselves to, take over caring responsibilities. Susan (family 4), took a more proactive approach to the emerging caring scenario. During the interview she stated in no uncertain terms that it would be her who would look after Jon should he require long-term care. While family members were happy to be involved in caring tasks, Susan took her involvement to a different level. She argued that:

I had been bed bathing Jon, I'd helped them roll Jon and I was quite happy. [] I wanted to do that because the way I looked at it, Susanne, we had no idea what condition Jon would come through this. And I would maybe have had to do these things for him a bit later down the line. And I just felt: 'I'm here, I'm as well might finding out now', you know, and getting used to it and getting over any kind of squeamishness or whatever.

It is evident in her comment that she purposefully wanted to be involved in his care. In contrast to other potentially designated carers in this study, she took the opportunity 'finding out now' what a caring scenario might mean for her 'later down the line'.

In this sense, uncertainty affected women's lives to a greater degree than was the case for other family members. It was the mother or wife 'who has to give things up' (Linda) while other family members could carry on with their lives. When probed in interviews it was not surprising that women found it more difficult to think forward and their reluctance to accept the enormity of the changes needed to accommodate long-term caring responsibilities were apparent in interviews. Beth (family 2), for example, asked poignantly 'future?' when she discussed the implications of Brian's brain damage with Ross, their son. While Linda had already informed her swimming club, that they 'won't see me again because I can't have any commitments – ever.' She nevertheless voiced more than once her hope that Hamish will make a substantial recovery. This foreshadows the long-term nature of caring for a brain damaged family member and the impact this has on the future lives of main carers. In her case, she hoped that she could keep her job. Not just because she liked what she was doing but also, as she pointed out, 'for my own sanity'.

Fiona's sadness and tears during the interview at times when future issues were discussed indicated a similar desire to keep her independence. In this context she remarked at one point that they 'wanted back our own life'. This is what she referred to when she said that she was frightened of the future because of the uncertainty which related to Kieran's unknown care needs and therefore to her degree of independence. The brain damage in both patients had the potential of changing the long-term future of both families. From a family life-cycle perspective children are 'launched' into their own independent lives at some point (McGoldrick and Carter 2003). Brain damage puts this developmental step in jeopardy. Actually, Hamish (19, family 5) had already lived independently and now this step would be reversed due to his emerging care needs. In taking on the role of main carer, both women were asked to sacrifice parts of their identity and independence for the needs of the family.

It is tempting to argue at this point that gender and power inequalities in families are responsible for this one sided situation. It seems that the assumed 'naturalness' of women's caring abilities predisposes them to take on any caring roles that emerge during a family's life course (Bernardes 1997). In fact, as some authors point out, even the state draws on the family as the site of care as is evident in local as well as national public (health) policies (Wasoff and Dey 2000, McKie et al. 2004). Family in this context reads 'woman'. To see care as gendered is not a new insight (e.g. Morgan 1996, Bernardes 1997, Muncie and Sapsford 1997, McKie et al. 2004). Gender, as a social structure, affects our being in public as well as private spheres of life (e.g. Morgan 1996, Risman 1998). In addition, power in families or marriages has been linked to money and hence inequality within families or partnerships. There is the argument that the partner with the largest income is more likely to dominate the decision making, while at the same time women are characteristically in part-time and/or in lower paid positions (Muncie and Sapsford 1997, Vogler and Pahl 1999). Thus, as Muncie and Sapsford so persuasively argue, 'free and equal individuals tend to be men; women are neither structurally equal nor, if mothers, free' (Muncie and Sapsford 1997: 30).

The above excerpts all contain elements of these positions. Apart from Susan, who worked full time and supported the family, all other women mentioned worked part-

time in lower paid professions compared to their husbands. It is likely that they worked part-time because this allowed them to fulfil their various roles as mothers, wives and individuals. The economic disadvantage of women disadvantages them further in that there was little discussion about who would take on care responsibilities. While the feminist argument of inequality for women in marriages and families can be applied here, it fails to explain the 'relational connectness' in families that constructs family life as family life, ignoring the complexity and dynamic in family systems.

A relational stance seems more fitting in understanding what was going on. Thayer-Bacon's (2003) relational epistemological view sees knowing as something that is socially constructed by embedded, embodied people who are in relation to each other. In the context of families, this type of analysis is attentive to the dynamics in relationships, between individuals in families but also personal relationships which are located within larger social contexts. In emphasising a relational stance social structures, such as gender, still play an influencing role since this is part of the larger social context in which we live. More importantly, as Thayer-Bacon (2003:76) puts it:

Relations are transactional in that we affect each other, dynamically and functionally, and each is changed as a result.

It is this dynamic independence and interdependence of individuals in families that is of importance when considering families' reactions to emerging caring scenarios. To use a metaphor from systems theory: family members move in reference to each other and thus influence each other. In this light, the choice of who becomes the main carer was in both families a pragmatic one. The challenge for families in such a situation is to secure the financial future of the family, while at the same time, providing the necessary care for the care dependent family member. It was this line of thinking that prevailed in both families and underlay their choices.

It is important to emphasise that the men realised that their wives faced a different and difficult future. Jeff, for instance, said that he 'will have some sort of life, no matter how Kieran comes out of it' since he would return to his working life. Yet, family obligations were met in a way that secured the future of the family and decisions were based on this objective, not on gender. It is the transactional nature of actions in

response to a situation that travels through a family system which results in different outcomes for individuals in families. At the same time it would be naïve to think that social structures, like gender or power, are not part of the situation. This is what Thayer-Bacon calls ‘embeddedness’ since we are embedded in the larger social context. The feminist argument might seem pervasive but it is simply not the whole story. The intimate relationships in families, socially constructed by their embedded, embodied family members that affect each other dynamically and functionally, are the other part of the equation.

Caution has to be exercised in generalising these particular study findings since my data is influenced by two special factors. The women in this study themselves expected to take over caring responsibilities and in the blended families all children were biologically linked to the women. Hence, it is possible that these mothers saw it as their responsibility to take on caring responsibilities because the patient was biologically linked to her and not necessarily to her partner. As pointed out earlier, Susan (family 4), for example, deliberately and purposefully wanted to be involved in Jon’s care. She very pragmatically argued that she might ‘had to do these things for him a bit later down the line’ anyway. There was never a doubt in her mind that it was her and not Clive’s responsibility to look after Jon.

Another reason lies in the sample itself. I was not able to recruit a family with a female patient and a healthy male counterpart taking on all family responsibilities (see Chapter 4). Therefore the experiences of men facing main caring responsibilities are absent in my study. In this context, Risman’s (1998) conclusion that men, should the necessity arise, can also ‘mother’ and that children are not necessarily better nurtured by women than men (Risman 1998:70) is of importance. In the context of emerging long-term care situations it is important to recognise that ‘free choices’ are made within social constraints (Risman 1998). I concur with Risman’s view that this is true for both genders. In this sense, gender does obscure family (Morgan 1996). Social constraints have the potential not only to inhibit women but men too.

Ambiguous loss

In families, where the patient had suffered brain damage, participants spoke of their loss. The notion of ambiguous loss, which was introduced by Pauline Boss, a family therapist from the United States, is of help here. Boss (1999, 2006) distinguishes between two basic types of loss. In the first case, a person is *physically* absent but psychologically present in the family. The literature gives missing children or soldiers as extreme examples of this type of loss (Lewis-Fravel and Boss 1992, Boss 1999, DeYoung and Buzzi 2003), while a more everyday life example might be a family situation post-divorce where a parent or a child is viewed as absent (Boss 1999).

The second type of loss refers to a family member who is physically present but *psychologically* absent (i.e. after brain injury, Alzheimer patients, some mental illnesses). Jones (2002), using the grief process as framework in a phenomenological study investigating the impact of mental illness on families, provides such an example. The ambiguity of the loss was evident when families described their time of loss as a ‘marked discontinuity in the behaviour and being’ while their ill family member was portrayed as ‘being separate from the true self’ they used to be (Jones 2002:37 & 40). It is this type of loss, where the family member is physically present but psychologically absent, that is also of interest in the context of families with a brain damaged family member.

The issue of an ambiguous loss emerged first in family 2. Brian had suffered a hypoxic event resulting in brain damage. Beth, his wife, and their adult son Ross (25) discussed Brian’s brain damage in the context of medical advances. Beth compared the current state of knowledge about the brain, as medical staff had explained it to her, with advances in organ transplantation, arguing that ‘twenty years ago nobody did heart transplantations, whereas now it is routine.’ It was her belief, based on a classical biomedical perspective, that advances in brain research would answer the family’s most pressing question, namely that of the extent of recovery one might expect for patients like Brian. Ross had a different understanding of the situation.

Beth: What do you mean? What do you mean? It's not the same as what?
(*higher pitch, sounds anxious*)

Ross: As these heart transplants or mapping DNA or anything like this.

Beth: Oh! You mean finding out?

Ross: I think there is a fundamental problem.

Beth: Oh, you just mean that people don't know much about the brain and how it works, and-

Ross: What I mean there is (.2) I think, there's a fundamental problem. Why do people still go to church? Why do people still believe there's a soul?/

Beth: /Yeh (*exhales*)

Ross: All they can do is tell you that there's electrical activity and body functioning. It's like he's not really there- like, you know, the essence of who he is, is not there. And I don't see how they're going to be able to pin down the essence of what someone is, because that is clearly something, which does not fit in with the physical things. They may make great leaps in reality in short periods of time over- for ah, a lot of physical stuff, you know, even mapping human genomes and knowing all about the DNA and everything. Potentially they can ah, they can genetically eradicate various diseases and, you know, even grow human beings, but again there's a fundamental problem within growing human beings, they don't know what the essence of that person is, because it's like his body is there but it's really hard to see that he is still there because you don't get anything, you know, nothing comes forward.

Beth: Yeh. (*reflective*)

Ross: You can't see that he's there.

While Beth sustained her hope of a recovery by clinging on to a knowledge limitation in neuroscience (clinical uncertainty), Ross carefully proposed that his family had actually suffered a loss. He very accurately described the definition of an ambiguous loss due to the psychological absence of the individual. His understanding of the ambiguity of their loss is evident in comments like 'the essence of who he is, is not there' or 'his body is there but it is really hard to see that he is still there because you don't get anything' and 'you can't see that he is there'. In Ross's own words, it is the 'essence of who he is' that has gone, leaving a functioning body behind. Substituting the word 'essence' with 'soul' enhances understanding of the situation. If 'essence' stands for the 'fundamental nature or inherent characteristic of a person' and 'soul' is understood to be 'the moral, emotional or intellectual nature of a person' (Concise

Oxford Dictionary, 1995) then the ambiguity, extent of the loss suffered and implications for the future of that family becomes apparent. It is the ongoing nature and high level of clinical uncertainty as to what has been lost of a person's 'essence' that links clinical uncertainty to the difficulty in mapping one's future.

The above excerpt is also an interesting example of how individual family members constructed and reconstructed meaning in and of a critical illness situation. Ross very skilfully questioned Beth's belief in medical advances and her hope for eventually finding a way to 'cure' brain damage. He actively reframed Beth's belief by offering a different perspective of the situation. At the beginning of this interaction Beth was clearly hanging on to her belief in a cure. This was also evident in her tone of voice during this interchange. In a slightly panicky voice (higher pitch) she asked Ross 'What do you mean? What do you mean? It's not the same as what?' By the end of this interaction Beth had reflected on Ross's comments and seemed to have agreed with him. Beth, like Ross, had understood the link between clinical uncertainty and the ambiguity of their loss. Yet, they differed in their acceptance to this insight. While Ross was in an early process of accepting that the 'essence' of his father had gone, Beth still hoped for a cure. Similar to Jeff (family 8), Ross had commented that he 'will eventually go back to his own life' while Beth, as argued earlier, remained uncertain about her future. For her, in a similar way to Fiona and Linda, the implications of Brian's survival but severely brain damaged meant taking on caring responsibilities.

In listening to families of brain damaged patients it became evident that they had suffered a loss which was substantiated in their own language. These families talked about their family member in the past tense. They talked about 'he was a good golfer' (family 8) or 'he had the world at his feet' (family 5) or 'he liked New York' (family 2) and so on. The losses these families had suffered crept into their thinking and language without it ever being acknowledged as loss at that time. Jones (2002) reported a similar observation in families with an mentally ill family member and suggests that this underlines the difficulties families encounter in reconciling the memory of someone, prior to mental illness, with the person today.

Boss (1999, 2006) describes the experience of ambiguous loss as traumatic because of the inability to resolve the situation. It is the ongoing nature of ambiguous loss that challenged families further. In contrast to death, there is no closure and no resolution. Mourning has to take place with the person physically present yet psychologically absent. One of Jones's family members explained this complicated grief situation as 'living on the edge of the world' because it is so difficult for others to understand what is happening in families that have lost someone in such ambiguous ways (Jones 2002: 51). The ambiguity of the loss causes confusion and suffering in families. Julie (family 3), Peter's wife, recalled that she had accepted Peter's loss when she was informed about the severity of his brain injury. His survival emotionally confused her and she said 'but he is still alive and I feel guilty for thinking that.' Beth (family 2), Brian's wife, revealed similar emotions in saying

'If he'd have died last Tuesday, like – if we lived two minutes further away they wouldn't have been able to get him round. And you'd have to deal with the fact that he'd died suddenly like that.'

These comments suggest that dealing with a sudden death is certainly traumatic and stressful but eventually part of human experiences. An ambiguous loss, in contrast, leaves families suspended in time and space. There are no rituals of saying good-bye and moving on. Society and other family members usually expect this family to take on caring responsibilities, creating a situation where the loss is diminished in its importance. I concur with Boss (1999) when she argues that ambiguous loss is the most stressful of losses. The ambiguity and uncertainty has a profound effect on family dynamics and roles. Jeff (family 8) underlined this view in pointing out that Kieran's brain damage 'has changed my life. It has changed our life.' This is where mapping the future and ambiguous loss conceptually link. While my emphasis in 'mapping the future' refers to the impact of an emerging caring situation on the family, the experience and uncertainty of an 'ambiguous loss' describes the psychological background this adjustment takes place. It is the extraordinary situation of losing someone and yet not losing someone, the ongoing nature of an ambiguous loss that challenged families' ability to move on in life.

Summary

In this chapter I have identified clinical and functional uncertainty as the families' core experience during critical illness. I followed the emergence of uncertainty from the onset of critical illness through to the time a patient spends in ICU. Subsequently, I laid out and examined the impact uncertainty had on families. With respect to everyday life situations my findings reflect a number of other study findings (Titler et al. 1991, Craft et al. 1993, Hupcey and Penrod 2000, VanHorn and Tesh 2000). Families described critical illness and the admission to ICU as traumatic, which was underlined by their expressed emotional responses on learning about the critical illness. The core experiences of families during critical illness however evolved around the different aspects of uncertainty. Uncertainty in this context is two-dimensional: firstly, clinical uncertainty and secondly, functional uncertainty.

Clinical uncertainty emerged in situations where the aetiology, diagnosis or the prognosis remained uncertain for the foreseeable future. Clinical uncertainty refers to the unknown and unknowable aspects of critical illness. Families found it difficult to accept and adjust to sustained uncertainty inherent in critical illness.

Functional uncertainty, in contrast, differed from clinical uncertainty in that this aspect of uncertainty focused on managing a clinically ambiguous situation. Functional uncertainty was used as a means to manage individuals or groups during an illness situation for one's own functional gain. Similar to clinical uncertainty, the communication strategy used was guided by ambiguity, attempting to keep all possibilities open for the future. Functional uncertainty in this study was evident firstly, in interactions between health care professionals and family members and secondly, in interactions within families.

I suggested that an important aspect of clinical communications was not to resolve all uncertainties but to preserve it for the functional gains of concerned parties. Maintaining a degree of uncertainty provided health care professionals with flexibility in their approach of treating a critically ill patient. Parents used uncertainty to buy themselves some time to cope and deal with the demands of critical illness but also to

instil hope in their children for a positive outcome. These were functional gains resulting from preserving uncertainty.

In the following chapter young people's experiences with critical illness and their struggle to access information will be examined in more detail.

CHAPTER 7

Young People's Experiences with Critical Illness and Strategies to Access Information

Introduction

In this chapter I present my findings relating to young people's experiences with critical illness in their families and the strategies they employed to access information.

'Keeping normality in life' and 'fishing for information' emerged as themes of young people's experiences with critical illness in their families. The activities leading to both themes were direct results of clinical and functional uncertainty and power asymmetries in families. I argued in the previous chapter that strategies of withholding information and evasion (Davis 1966, McIntosh 1977) were evident in family communications. The objectives of functional uncertainty in families were related: firstly, to protect children from the stresses and strains of critical illness and secondly, to create some space, time and respite for the parent's own coping with the pressures and strains of critical illness. Yet, young people developed their own strategies to cope with critical illness and access information in order to generate meaning in their current situation. The different dimensions of 'fishing for information' are linked to young people's understanding of critical illness in the context of ICU. Two different levels of understanding emerged. Younger children tend to understand the ICU on a concrete level, which was evident in their focus on 'ICU as environment'. Older children or children with a prior ICU experience in their family understood the ICU on an abstract level which was apparent in their focus on 'ICU as function'

The focus of the following data analysis remains relational but includes a generational perspective in positioning individuals within their family in order to elicit its impact on children's experiences. A generational position is linked to power and status differences in families. Hence, an underlying assumption is that of power asymmetries in families. It is for this reason that I start with those who shape experiences for young

people before turning to the young people themselves to bring out how they negotiated space and status and thus co-constructed their experience.

‘Setting the scene’: Adult power in controlling information to young people

Childhood sociologists, including Qvortrup (1994, 2002), Mayall (2000, 2002, 2003) and Alanen (1994, 1998, 2001a, 2003), have argued for some time that the social phenomenon of childhood is a generational phenomenon. An in-depth discussion on the concept of generation is provided in Chapter 2. Here, it suffices to say that the notion of ‘generation’ points to the relational dimensions of childhood in that children or childhood can only exist in relation to adults or adulthood (Alanen 1994, James et al. 1998). This distinction between childhood and adulthood often defines children as ‘becoming’ while adults are viewed as ‘being’ – the unfinished child and the complete adult (e.g. James et al. 1998, Lee 2001). The implications of this perception are far reaching for children since power over and responsibilities for children are assigned to adults. Not surprisingly, adults and children understand childhood as a time of dependence and subordination (e.g. Lee 2001, Mayall 2002, Corsaro 2005). The dependence – independence debate is strongly influenced by developmental discourse and as such influences adult definition of children where emotional and cognitive maturity is linked to chronological age (Such and Walker 2004). The age-based developmental stages discourse however ignores life experiences and their influence on children’s social development throughout childhood. Ewan (15, family 1), for example, was a recognised young carer and had very different information needs compared to other young people in this study. Accordingly, understanding childhood predominantly as a time of dependency is misleading. Children, as a collective, are a diverse group. Childhood is inhabited by children, who are at different points in their development and these points may or may not be related to age. Power, which is associated with dependency, is a similarly slippery concept in that power asymmetries in families are not static but dynamic over the course of childhood (Kuczynski 2003). It is the adult’s perception of children that defines their ‘need for protection’ and emphasises power asymmetries between children and adults and influences children’s experiences with critical illness. Of relevance here is Alanen’s argument that:

[] in order to detect the range and nature of the agency of concrete, living children, the exploration needs to be oriented towards identifying the generational structures from which children's powers (or lack of them) derive: the source of their agency in their capacity of children is to be found in the social organisation of generational relations (Alanen 2001a:21).

In listening to young people it became evident over time that their struggle to access information relating to a critically ill family member can be attributed to their generational position in families and society. 'Controlling information' emerged as a further functional uncertainty aspect of withholding information which was used by parents specifically to protect and reassure their child during critical illness. In employing this strategy parents literally controlled the flow of available information relating to critical illness to their child.

Controlling information

At the beginning of the interview, family 4 reflected on the events surrounding Kieran's accident. It was at this point where it emerged that Jody (15) had been out of the house when Fiona and Jeff (parents to Kieran (17) and Jody) learned about Kieran's accident. Consequently I asked her:

SK: Where were you during this time Jody?

Jody: I was out when my mum came. So - I phoned and she said she was coming home to get me.

Fiona: I phoned. I phoned when we'd got back out of the car at the scene, I phoned my friend Lucy because Jody was with her daughter anyway. (.2) And there's a lot of kids with mobile phones and the wee boy who lives next door to us was on his bike at the accident with his mobile phone, and I thought I didn't want Jody to hear it from anybody else. So, I phoned Lucy and said to her that Kieran has been in an accident and it didn't look good and she should get Jody and bring her in just say to her so that she didn't, didn't hear of it from anybody else. (.4) And we went- what did you do? (*Towards Jody*)

Jody: Ah, I spoke to () could you come inside please (.2) and Lucy said she couldn't find out what happened, that's when she came up-

Fiona: /she came up to casualty-/

Jody: /she came back and she told us. We just sat there for the first few (minutes) I think it was, and then we went out.

It is important to bear in mind that this family lived in a small town where people know each other. The accident triggered a major response from emergency services including the fire brigade who had to cut Kieran out of his car. Fiona's thinking and subsequent response at the time suggests that this kind of 'action' would not go unnoticed for long. She was aware that children have mobile phones and that there was a possibility that Jody might learn about the accident through others. The above describes a *despite/because* situation, which was evident across participating families. It was *despite* the seriousness of the situation that the information needs of a child were considered. At the same time it was *because* of the seriousness of the situation that the how, when and what of information giving was of particular interest to parents. It is this aspect of managing the information flow that is linked to functional uncertainty. In this example, Fiona as the mother takes charge of the situation in that she controlled the information provided to Jody with regard to: content of information, timing of giving information, the way in which information was relayed to Jody and who was giving the information. A number of parents used their parental power to manage information and shield their children from the uncertainty of critical illness.

From Jody's perspective it was her mother's understanding of the seriousness of the situation that started to construct Jody's first experience with critical illness. Fiona's motivation to control the information to Jody was driven by her need to protect Jody from hearing it 'from anybody else' but a trusted adult, in this case her friend Lucy. It was Fiona's understanding of Jody combined with the seriousness of the situation that required that Jody got the facts in a manner reflecting her perceived needs. Yet, for Jody, it was not one of her parents who informed her about the accident but a family friend. It was Lucy, Fiona's friend, who went to hospital without Jody to find out what had happened. At that time Jody had no opportunity to ask any questions or access further information. In effect, Jody was left in a state of uncertainty, waiting for further decisions by adults as to what happens next.

Jacky (family 6) reacted very similarly to Fiona in that she considered the news of Dave's hospital admission on Anna. Yet, her response differed. Jacky waited for

Anna (16) to come home from school before setting off to hospital. I had probed as to why this was so important.

Jacky: Well. She, she (*Anna*), I knew she would be mad with me if I went away without her. I know what type of girl she is and she'd be furious if I'd left her. And I only needed five minutes to wait on her because I'm right - 'cause the school is right next to my house and I knew I could get Anna quick, but if I hadn't have been able to get Anna quick I would have left her. But I knew that. That I could get Anna in 5 minutes, so she ran all the way home. She could hardly breathe actually because she actually thought (.2) Dave had died. (.3) I think. (.2) I don't know why? (*looking at Anna*).

Anna: Mhmm. (*confirmative*)

The family had actually two children: Rose (17) and Anna (16), living, similar to family 8, in a small community where people know each other. While Anna was at school at the time of the incident, Rose was home and knew what had happened. One of Anna's friends had suffered the sudden loss of her father the previous year. As is evident in the above excerpt, Jacky suggested a connection between this earlier experience and Anna's need to be involved. It was Jacky who voiced her suspicion of an assumption on Anna's part that her father might also have died. That view was supported by Anna's later comments during the interview in which she described her panic that 'something bad had happened'. It became clear that 'bad' was Anna's way of paraphrasing 'death'.

In 'waiting for Anna' Jacky's wish to involve her youngest daughter was based on protection but also reassurance. The protection issue refers (similarly to Jody's experience) to the small community the family lived in and the need to control who gave what kind of information and when. Reassurance was linked to the above described prior experience of Anna's friend.

Parents across the study viewed protecting their child from distressing family illness situations as part of their responsibilities. This is evident in the above presented data but also in other families where parents wanted 'the doctor to stop and let me see to him (*Ewan*)' in order to explain what was happening (Pam, family 1), or for instance in family 4 where Susan 'came up on Saturday or Sunday because I wanted to speak to

Alan, I wanted to speak to Alan himself and I tried to explain as much as I could without scaring him' or where when Julie (family 3) explained the link between Peter's non-responsiveness and the effect of sedation to Fay and Mona during the interview. In this sense and as is evident in the above data, in managing the information flow and gradually building up information (e.g. McIntosh 1977), the strategy functioned in safeguarding their child's mental well-being. 'Controlling information' in such a way is however only possible because of power asymmetries in parent-child relationships. In sociological or health care (research) writings it is widely accepted that parents, or adults more generally, hold power over children and are gatekeepers to them (e.g. Coyne 1998, Mayall 2000, Kuczynski 2003, Robinson and Kellett 2004, Corsaro 2005, Hill 2005a).

The subtle, yet important, difference between the two examples lies in the way parental powers were exercised. In Jody's case, adults decided to protect her by not bringing her to casualty, which at the same time prevented her from accessing information, while in Anna's case, the decision to go to hospital rested with her. The notion of separation and separability, as discussed by Lee (2005), is helpful in understanding how parental power shaped the experiences of both girls. His discussion of separation and separability refers to the implementation of children's right to participation in all aspects of social life and, if taken seriously, the consequences this would have for parents or adults more generally in terms of their authority over children. Separability, he argues:

'is simply the possibility of children's temporary and partial separation from their carers, communities or cultures, the possibility that they might be considered for their own sake beyond the claims of those they otherwise 'belong to' (Lee 2005:37).

In contrast, the idea of an actual or complete separation within the adult-child relationship constitutes a threat to adults' authority over children. Living in a family suggests a certain degree of interdependence between family members. Yet, there is a part of a person that is separate from the family, which Robinson (1995a, 1995b) terms the 'individual'. This distinction allows us to conceptualise the family on different levels, namely that of the 'person as individual separate from the family' and that of a

‘person as a family member and their relationships’. It is the separability of individual members that is of importance: for being separable does not mean being separate. This is what some authors call the ‘fundamental duality of family life’ (e.g. Hess and Handel 1959/1995, McGoldrick and Gerson 1989, Broderick 1993). Mistaking separability for separation functions to deny individual family members the part of the person that does not belong to the family but to the individual. In my view, this is true for children as well as adults in families. In the context of children, this misunderstanding leads to situations where young people are denied their ability to act in their own interest.

What this discussion also emphasises is the tension between the view of childhood as a time of dependence, suggesting the need for protection, embedded in the love and responsibilities of parents towards their children and the right of a child to actively participate in society. It is important to assert that dependency during childhood and power asymmetries in families do not equal passivity. The strategies children employed to access information, outlined below, are testimony to this. Children are frequently understood as social actors, who actively construct their own lives within their social context, including their families (e.g. James and Prout 1997, Mayall 2002, Jenks 2004, Corsaro 2005). Importantly, participation in the sense of ‘being’ and acting in society is not age related (Alanen 1994) but starts right at the beginning of life. A toddler having a tantrum while shopping with a parent because he or she does not get the object of desire (e.g. a sweet or toy) is an example of a young child’s ability to act in his or her own interest.

In reference to the above examples, it is apparent that Jacky’s reaction considered Anna’s information needs as separate from hers and hence provided Anna with enough independence to act in her own interest. In contrast, adults failed to see Jody’s ability and right to participate at that particular point. As a consequence, a situation which could have been Jody *with* adults in the Accident and Emergency (A & E) department turned to a decision by adults to protect her, which effectively denied her the opportunity to decide for herself. ‘Protecting’ or ‘shielding’ children emerged alongside adults’ failure to recognise the emotional impact the situation had on children (Baker et al. 1988, Dale and Altschuler 2006). The rationale from an adult

perspective for ‘protecting children’ was discussed in the previous chapter. Here, it suffices to say that parental decisions in all above given examples were made with the ‘best interest’ of the child in mind. The acceptance or rejection of a child’s ability and right to participate and act on their own behalf is of central concern when examining the experiences of young people dealing with critical illness.

Children’s agency: keeping normality in life

‘Keeping normality in life’ was an area where children’s decisions actively constructed their experiences during critical illness. Going to school is a normal day-to-day activity in young people’s lives and serves as example. While all children had some time off school at some point following the ICU admission of their family member, the decision to stay home and for how long in some cases rested with the child, while in others a parent made this decision. This difference draws attention to children’s agency. I pointed out above that children are understood as social actors: agency, however, as Mayall suggests goes further. She argues that the term ‘agent’ implies:

‘negotiations with others, with the effect that the interaction makes a difference – to a relationship or to a decision, to the working of a set of social assumptions or constrains’ (Mayall 2002:21).

The difference between a social actor and an agent then is the acceptance of the temporary and partial separability of a child from his or her carers, communities or culture in recognising and respecting their ability to act upon their own interests. In this study, negotiations with others were primarily within the family context. Perhaps more subtle, yet of importance, are those interactions taking place in ICU as part of the health care system and thus society. Consequently, in families where a child was perceived and respected in its aspect of a ‘person as individual as separate of the family’ (Robinson 1995a), the child had the freedom to act in his or her own interest. In short, decisions rested with children. In cases where children decided that they wanted to go to school, school provided a routine and structure that functioned in reassuring them that not everything in their life was off balance. ‘Keeping normality’ in their lives was one way for some young people to cope with clinical uncertainty and its related stresses. Fay (12, family 3), for example, discussed her busy social calendar

with her mother during the interview. Asked why this was so important to her, she argued that ‘seeing friends’ and ‘doing normal stuff’ was part of her life. It became evident that young people used school settings as a place away from critical illness, taking a break from what was otherwise a very stressful and uncertain time in their lives. This finding concurs with Dale and Altschuler’s observation of children in families with a seriously ill adult who perceived school as a ‘safe haven where they can be sure of boundaries and the expectations’ (Dale and Altschuler 2006:426).

The opposite effect emerged in families where parents made the decision for children. Family 4 can serve as example. Susan, the mother of Jon (19), Carrie (18), Alan (13) and Ben (7) mentioned in our pre-interview conversation that she did not want the boys, Alan and Ben, to be exposed to any ‘Chinese whispers’ and took both out of school. Jon (19), their bigger brother, had suffered a serious brain injury leaving his survival in question. I knew that both boys were back at school at the time of the interview and was particularly interested in whether Alan talked to friends about Jon’s critical illness. I had asked him how long he had been off school.

Alan: Ahm, for two weeks I think. (*Looking at his feet*)

Susan: About a week and a half, then he went back.

Alan: Aye.

Susan: Then he went back. (*Looking at Alan*)

Alan: Back where I was supposed to be. (*Looking at his feet*)

Throughout this interaction Alan did not look at his mother. It became apparent during the interview that Alan and his sister Carrie (18) felt left out and cut off. They felt left out of the critical illness situation because Susan and her partner Clive, and their biological dad, were at Jon’s bedside and therefore unavailable for them at a time of need (e.g. Craft and Craft 1989, Lewandowski 1992, Hupcey and Penrod 2000). Alan in particular felt cut off because staying at home also meant that he could not see his friends. With his parents in a different city at Jon’s bedside and his friends at school Alan was left without access to his usual support network of family and friends. When asked if he had talked to his friends about Jon’s critical illness Alan answered:

No, because they were at school.

Taking Alan out of school might not have served his interests and is emphasized by him when I asked how the going back to school was he answered 'fine, aye' pointing out that he 'was back where I supposed to be'. Susan's chosen strategy to protect his psychological well-being by gradually building up his knowledge about Jon's critical illness through remaining in control of the information flow was in contrast to Alan's comments and non-verbal communication which suggest that had he had the opportunity to make a decision on his own behalf, would have chosen to stay at school. Alan's generational position was defined by Susan as a dependent child 'being in need of protection', underlining power asymmetries in the family. Parents protecting their children from critical illness frequently made decisions *for* their children instead of *with* them. Here, Alan was denied his normal 'going to school' routine and consequently access to the structure and social network that could have provided him with respite during a time of uncertainty.

Functional uncertainty: children withholding information

The realisation that children used the same functional uncertainty strategies of withholding information and evasion as adults did when they talked to school friends was somewhat unexpected. They mentioned the hospital admission to school friends in passing but withheld the seriousness of the illness. These strategies functioned in similar ways to those described in Chapter 6, namely as self-protection from emotional overload and a defence of normality in their lives. Ewan (15, family 1), for example, had not discussed with any friend the fact that Graham had been admitted to ICU while Connor (11, family 7) pointed out that he 'hadn't told anyone' how sick his dad really was. He continued by saying that he had told only three friends, one of whom had asked why he was off school that 'my dad was in hospital.' Emily (8), Connor's younger sister commented that she 'just said my dad's in hospital and he had an operation' to her friends and teachers but nothing about the seriousness of the illness while at the same time she spontaneously offered the information that she had 'told all my class and two teachers that my dad is in hospital.' The hospital admission of a family member was disclosed to explain their absence from school rather than revealing the seriousness of the situation.

Mona (10, family 3) and Fay (12), her sister, handled the situation similarly. Mona had told more classmates and friends that her dad was in hospital while Fay was selective in whom she let in on this knowledge. Like Connor and Emily, they had both told friends about their dad's hospitalisation but withheld the gravity of the situation. While self-protection and maintaining normality is one reason for this another emerging issue related to depth of understanding.

Some nurses offered useful insights from their experience of working with young people across age-groups. I asked nurses in focus groups what they thought young people's understanding was in relation to critical illness.

F 2: I think they understand the fact but maybe not the implications.

F 1: Mhmm. (*confirmative*)

F 2: You know, they understand what you're telling them but I don't quite know what that, in sort of, infers or what is gonna happen. I'm not sure.

F 1: I think they understand stuff like 'mummy is asleep' or 'daddy is asleep', you know, and that they've got tubes and machines and things but I don't know if they really know/

F 2: / understand/

F 1: /what could happen or-

F 3: What might happen.

F 1: Mhmm. (*confirmative*)

In another focus group a very similar perspective was offered.

S 1: I – well in my experience, I find that the group of children who seem to be more nonplussed by that are the six- no younger than that actually, the four year olds and younger. Five year olds, six year olds, it depends on the child. And I've found that people that react most adversely are the teenagers.

Whereas the young children just see dad hooked up to various bits of equipment and their natural curiosity kind of takes over (*group agreement: mhmm, yeh*)

And they're sort of nonplussed, and as long as you greet them with a smile and make almost a game out of it, I know that sounds really bad, you sort of introduce them and give them stethoscopes, they actually seem to accept it a lot

better, and it's the older children that I find look worried and look apprehensive and much more uncomfortable with it.

These contributions draw attention to the fact that nurses construct children's understanding of critical illness as markedly different between age groups. It appears from the above presented data that younger children tend to accept the situation at face value while older children interpret the ICU environment as indicative that someone's life might be threatened. It is at this point that a number of authors link a child's level of understanding with developmental theories as a foundation for nursing interventions (e.g. Baker et al. 1988, Pierce 1998, Lewandowski 1992, Clarke and Harrison 2001). Using a developmental approach as orientation is useful if one bears in mind that life experiences do influence children's reactions and understandings in general. Here, participating nurses' observations of older children looking 'worried and apprehensive' and being 'much more uncomfortable' was interpreted as this age group having 'more of a perception' of what critical illness meant. These observations of older children triggered a very different response from nurses than the younger child who could be engaged in a 'game like' approach to understanding. The two key aspects that shed light on young people's understanding of ICU relate to 'ICU as environment' as opposed to 'ICU as function' and are discussed later in this chapter.

In the case of both younger children, Emily (8, family 7) and Mona (10, family 3) it is reasonable to argue that they did not fully understand the life threatening nature of their fathers' respective illnesses and any possible consequences. During the interviews both children were able to recall in great detail aspects of the ICU environment and their 'participation' in different nursing tasks (some nurses involve children of this age in writing down their observational data and so on) but none had any detailed understanding of their father's illness. Their focus was on 'ICU as an environment' not as a function. These are examples where the 'natural curiosity' (S1) had taken over. Younger children were very interested in the environment and some asked detailed questions but the consideration of different possible outcomes was not part of their understanding. Mona, for example, commented at one point in the interview that her dad's brain was 'like scrambled eggs'. The tone of voice (jokingly) suggested that she had not grasped the seriousness of Peter's brain injury.

In the case of Connor (11, family 7) and Fay (12, family 3) the situation was different. Again, both children lacked any detailed knowledge of their fathers' illnesses, but they were both mature enough to understand that the outcome was uncertain. In this respect Connor differed from Emily (8). His reaction to their father's critical illness reflected the impact of a prior critical illness experience in his family. Their grandmother had died on the same ICU two years before their dad fell ill. Connor was keenly aware that death was one possible outcome. At the beginning of his father's critical illness one of Connor's coping strategies was avoiding going to visit his father. Asked why he had waited to visit his father Connor argued that he 'did not like hospitals'. That his avoidance really was a coping strategy became evident later in the interview when his mother, Sarah, pointed out that he had visited his Granddad in hospital and that at that time he had no dislike of hospitals. In response to her comment Connor answered that 'hospitals don't really bother me'. Emily, his sister, coped the opposite way - she needed visible reassurance (e.g. Lewandowski 1992, Craft et al. 1993, Nicholson et al. 1993, Clarke and Harrison 2001). Emily was keen to visit; even though it was upsetting for her. When asked how her first visit was, she commented that:

Emily: The first time I started crying, but the second time I was fine because I saw him all wired up the first time.

SK: And that scared you?

Emily: Yes.

SK: What was he wired to?

Emily: Ahmm. He was wired to all these machines like temperature and/

Connor: /the pee sack.

Emily: Yes. The first time I went he had a bio bag. It was right next to him because like all the stuff in his stomach.

Sarah: There was a bag beside him with some green stuff in it.

Emily: It's called a bio bag.

Sarah: A bio bag? Who told you that?

Emily: I read it!

On different occasions during the interview Emily discussed her detailed observations suggesting that her focus was on the 'ICU as environment' and not really linking 'wired up' with the seriousness of the situation.

Fay (12), like Connor, was uncertain about the extent of her father's illness and its outcome. Similar to Connor, Fay pointed out that what she had 'really told them (*friends*) was that he was in hospital. I don't tell them much.' This suggests that she too withheld information on purpose when talking to friends. She questioned her mother repeatedly during the interview in relation to her dad's condition. Her questioning suggested that she was looking for clues from her mother and interpreted the lack of information as information being withheld. This in turn made her suspicious as to what was going on. Lack of information had an impact on her understanding and ability to assign meaning to the situation.

Withholding information or being evasive with friends had two different aspects. The more obvious one related to functional uncertainty and the gain for the child involved. Going to school provided children with some respite from the family's critical illness situation. Withholding information was a necessary strategy to protect themselves from curious questions by others (i.e. friends or adults) and essential to maintaining normality. That withholding information was an important part of this strategy was emphasised by Carrie (18, family 4) arguing that:

'we kinda of like – like () at school, everybody comes up and keeps asking us, but because my mum, Clive and my dad were always here (*hospital*), they didn't see that part of it. People aren't bothered how you feel, they just wanted to know what's happened.'

It was this kind of additional emotional stress which children actively avoided by withholding information and taking control of their experience of critical illness in their families.

The second aspect, however, related to children's understanding or lack of it of the seriousness of the illness. The notion that children understand ICU either on a concrete or abstract level is of importance here. From the data it appeared that younger

children who viewed the ‘ICU as environment’ did not necessarily understand the implications of a serious illness. Emily (8, family 7), for instance, explained that:

Emily: And he (*her dad*) had all these needles in his arm.

Sarah (mother): I know. Like snakes.

Emily: I know because I’ve helped. They were just moving the thing around so that he had just the needles where he needed them.

In another family the children described their father in ICU the following way:

Fay (12, family 3): He looks like he was in Matrix⁸.

Mona (10): All the tubes and stuff.

Fay: Yeh. Lots of tubes.

Mona: And its like – he’s got so many, like tubes and stuff going out of him that it was like in the Matrix.

As is evident in the above data, the discussions emerged around the ICU as environment. The discussions during the family interviews remained on the environmental level and did not question the necessity or the meaning of various IV lines through which a cocktail of drugs (e.g. sedation, inotropes, vasopressors and so on) was administered, suggesting that they did ‘not really understand the implications’ (F 2) of what they were seeing. In this situation, there was literally not much children could report or disclose to friends in relation to possible long-term life outcomes. In contrast, older children, who withheld information, were more likely aware of their own knowledge gaps in understanding the implications of the situation. Anna (16, family 6), for instance, explained that ‘you’re too scared to think what the future will be like and that as well.’ She specifically made a point of not up-dating her friends on the situation but withdrew which was evident when she said that ‘I’m not bothered meeting my friends just now.’ In this sense, withholding information reflected the young’s person uncertainty about his or her illness knowledge. The issue of ‘ICU as environment’ and ‘ICU as function’ is further developed later in this chapter. Here, it

⁸ The Matrix is a Science Fiction film. Actors are floating in tanks and their bodies are connected to cables, including the head. The bold used to measure ICP pressure looks similar to those cables in the movie.

suffices to say that the difference between the two groups lies in the intention behind withholding information. In both groups, functional uncertainty related to children withholding information for their own gain, specifically to maintain normality in their lives. Some older children were also aware that they lacked information to fully understand the implications of the illness and were cautious about what they disclosed to friends. While this is another example of how children acted in their own interest and actively constructed their lives, it also draws attention to the existence of uncertainty and anxieties in children which ‘do not go away but remain albeit in an ‘unlanguaged’ manner’ (Dale and Altschuler 2006:429) if their access to information is restricted.

I pointed out earlier that dependency in childhood does not equal passivity. With this in mind, my analytic focus in the following sections considers young people’s agency and their strategies to access information.

Fishing for information

Over time ‘fishing for information’ emerged as a major theme from young people’s different strategies in obtaining information. ‘Being present’ and ‘direct and indirect questioning’ were the main strategies employed by young people in order to access information. The strategy of ‘being present’ which young people used to ensure inclusion in the critical illness situation and access to information will be explained first.

Being present: young people positioning themselves in the critical illness situation

A young person, accompanying a parent or partner while visiting the ICU does not necessarily appear as something extraordinary but rather reflects a daily experience for ICU staff. From this perspective, the presence of a young person might seem to be a passive, almost by default, incident which just happens to be the case because one family member required intensive care. On further analysis however ‘being present’ emerged as a strategy employed by young people acting in their own interests and upon their needs. The aim of this strategy was three-fold: firstly, access to

information, secondly, supporting the critically ill family member, and thirdly, supporting the healthy parent or partner.

Being present: access to information

The first dimension of 'being present' refers to the young person being *with* an adult family member during a conversation when either nurses or physicians spoke to family members about the critically ill person. Ewan's (15, family 1) experience can serve as example. Before being transferred to the study hospital, Graham was admitted to their local hospital. Right from the beginning Ewan positioned himself as a 'silent listener' in the information loop when Pam, his mother, received information about Graham's health status. In using this strategy, Ewan ensured his access to information.

After Graham was transferred to the study hospital Ewan (15) continued with this strategy of positioning himself in conversations as 'silent listener'. At this point in the interview I was interested whether he was actually a conversation partner during these interactions in ICU and whether health care staff was talking directly to him.

Ewan: Not really. (0.8) They were mostly talking to my mum. They were telling (her) what was going on. I was listening to it all.

Pam: Yep, there was nobody actually, nobody there to, really to take him aside and/

Ewan: /no one came up to me and gave me any information on how he's doing and what's happening and that.

While Ewan's presence was accepted during conversations between Pam and health care staff, he was not the addressee of the information. In his own judgment, he was not part of the interaction but just 'listening to it all'. There was one further incident, which supports the view that health care professionals accept the presence of young people during conversations but do not necessarily involve them. At that time Ewan had visited Graham with an adult family friend because Pam was suffering from 'flu.' In this situation it was the adult family friend who was the addressee of Graham's progress update. Ewan commented that 'she (*nurse*) just talked to Ella (*Pam's friend*) and ignored me' suggesting that he was assigned the role of 'silent listener'. It would appear from the above two examples that staff viewed Ewan as a 'non-adult', which in

turn manifested the order of the social world that views adults' interests and rights as different from, and often as more important than those of children (Mayall 2001). In doing so, nurses ignored family boundaries since Graham was part of Ewan's family but Pam's friend was just that – her friend. Not surprisingly, Ewan felt very strongly about this experience and commented that:

'I don't think that's really fair. I mean, I am old enough to understand what's going on. I think, I should be told as well rather than just standing behind and listening like children told by parents what's going on.'

In fact, it was this incident that led him to negotiate with his mother their participation in my study. In participating Ewan acted as agent in his own interest in that he purposefully contributed to the study, so that his experience can make a difference 'to the working set of social assumptions or constraints' (Mayall 2002:21) for other young people. I suggest that age, and therefore Ewan's generational position in his family and society, and not family membership was the key aspect in deciding who was receiving information. Ewan was a recognised young carer and in excluding him, nurses not only ignored his considerable experience with illness and caring for Graham but also his right to be involved and his need for information. Investigating problems and worries of 150 young carers Cree (2003) points out that 81% of young carers worried about the person they cared for. This explains Ewan's increased need for information and his disappointment about being excluded.

Being sensitised by Ewan's experience I probed in subsequent interviews for the situational circumstances in which families received information about their ill family member. I asked, for example, Family 6 the following:

SK: When you got that information on what was going on, that Dave would eventually be sent here to (*study hospital*), who was getting the information? You, as a wife or you as a group?

Jacky: All of us, aye. I'll let them come in.

Anna: Mhmm. (.3) Was this when - ? No, it was just the surgeon. The surgeon was up there and he said that my dad had a (.2) had a – like a blockage and fluid in the brain. He was probably talking to my mum but (.3) to all of us.

Anna was well aware that it was not herself and her sister who were the addressees of the information but their mother. Like Ewan, these young people found themselves as ‘silent listeners’ during an information giving interaction. Here, Jacky ‘let them come in’, which underlines adult’s power as gatekeeper to their information. The perception adults had of children regulated children’s access to information across families. In ‘being present’ young people circumvented an adult’s control and ensured that they had access to the information they needed. This strategy is similar to what Strauss (1978) called the ‘silent bargain’ negotiation. ‘Listening to it all’ was usually a passive activity in that children often did not ask any questions at that point. Over time however this differed between Ewan, Rose and Anna. While Ewan (15, family 1) and Rose (17, family 6) were rather quiet, Anna (16, family 6) started to enquire and asked for explanations once she had overcome the first shock of Dave’s admission to ICU.

Many nurses in this study reported that they encouraged parents to bring in their children. There is however a difference between accepting children as visitors in ICU and supporting them. A difficulty for ICU nurses arose in distinguishing between young people who were accessing information by asking and those who were not asking but needed information all the same. Discussing young people as visitors in ICU, I had asked nurses in focus groups whether there were differences between age groups and, if so, what these were.

E4: It’s the teenagers. They get more upset. (*group consent: yeh, mhmmms*)
The older boys (.3) (*someone in the group: mhmm*) because they think they’re not allowed to cry that can be really, really hard. They get upset and they don’t want to be seen crying.

SK: So, what do you do then when you realise this is going on?

E1: Well, a few weeks ago, I can’t even- it’s shocking I can’t even remember what patient I was looking after but I had a patient for a few days and he’d got a son who was 14 who came in twice, I think. Otherwise he spent a lot of time sitting outside the unit and talking to us.

E3: I find myself (talking) more to the teenagers that are coming. I will go out and speak to the person and explain everything to them, explain what the machines are doing and why they’re there, and about alarms and noises where I wouldn’t so much with the younger child. I don’t know why that is, I don’t know whether I expect, family or parents to do that, but I think for teenagers they have

a bit more of a perception and you know, a bit more of an individual- and I do go out and warn them about things 'cause I do think they probably take more in of something that's going on around the bed and noises and alarms and- so that they can have an understanding if an alarm goes that doesn't means something's not right.

The above group of nurses were not the only ones who made a particular point of 'going out' and 'talking to teenagers' before they visited someone in ICU. This was a phenomenon reported by nurses across focus groups. Teenagers were understood as having 'more of a perception' even, as one of the above nurses argues, being 'a bit more of an individual' and therefore had a more rational understanding of the situation and its possible implications. They are, in short, intellectually more mature. It is of interest to note that subconsciously a developmental approach crept into nurses' thinking about children and young people although developmental theories were never mentioned as such in focus groups. However, perceptions of young people as 'being more of an individual' or as having 'more of a perception' is linked to developmental approaches and the associated becoming – being debate, which is so lively within the sociology of childhood (e.g. Qvortrup 1994, James et al. 1998, Lee 2001, Mayall 2002, Corsaro 2005).

Nurses proactively targeted teenagers mainly for two reasons. Firstly, based on their belief that teenagers had 'more of a perception' of what was going on, they believed teenagers were in need of information before they visited the first time. This emphasises their developmental view of teenagers and the increased information need that resulted from it. Secondly, nurses expected parents or other adult family members to prepare younger children for an ICU visit. Interestingly, this was in direct contrast to nurses' behaviour at the bedside. Once in the unit, younger children were often involved in a 'game like approach' and 'doing' nursing tasks (e.g. writing down observational data, creaming hands and so on), while most nurses responded to teenagers in reply to questions rather than acting proactively. In assuming the role of a 'silent listener' quiet young people missed out on getting information and were left to wonder what was happening.

The perception of young people as 'non-adults' links to age and raises the issue of young people in social spaces such as ICUs or hospitals more generally. The notion

that ‘children are sited, insulated and distanced, and their very gradual emergence into wider, adult space is only by accident, by degrees, as an award or privilege or as part of a gradualist rite of passage’ (James et al. 1998:37) is of interest. In Chapter 6 and at the beginning of this chapter I outlined why parents protected their children from the stress and strains of critical illness. Not allowing children to visit was one such strategy. In this sense, children as visitors in ICUs draw attention to their presence in ‘their gradual emergence’ into what is essentially an adult social space. While the study unit had an information book for adults, there was no such resource available for young people. In preparing children to visit someone in ICU, some nurses used photographs showing a member of staff posing as a patient on a ventilator and other surrounding technologies. These photos enabled nurses to point out ICU technologies before children entered the unit. However, other written material, which could be taken home and read at one’s own pace, was not available. This is not an uncommon situation across the UK (e.g. Hartleib and Sibbald 2004, Vint 2005a, 2005b).

There is one further aspect to the strategy of ‘being present’, which was less obvious and used by some younger children. These children positioned themselves in a less visible way with the intention to overhear conversations their parents had with others, for example, on the phone where the subject was the critically ill family member. In this context, Julie (family 3), mother of Fay (12) and Mona (10), mentioned that Fay had been observed by another adult family member positioning herself in a way that meant she was able to overhear a phone conversation Julie had about her husband’s condition. Emily (8, family 7) light-heartedly let her mother know during the interview that ‘me and Connor were listening to you when you were on the phone the other day’ lending support to this covert aspect of ‘fishing for information’. Caution has to be exercised in generalising this finding to other age groups and families since this was only reported in these two families.

The second dimension of ‘being present’ served to fulfil young people’s need to support the critically ill person as well as the healthy parent or partner and is discussed in the following section.

Being present: supporting the critically ill family member and healthy parent or partner

Supporting the critically ill family member as well as the healthy parent or partner of the sick family member by 'being present' were two further dimensions of young people's strategy. Analytically these are two different aims since they focus on different individuals in a family unit and could be separated, reflecting the possibility that one can occur without the other. Whether this separation occurred was dependent on family functioning prior to critical illness and family 9 might serve as an example (see Family Profiles and below). In the majority of families in my study these two aims were closely linked and therefore are treated under one heading.

I realised over time that 'being present' was not only about getting information and probed young people by asking why 'being there' was so important to them. Chloe (18, family 9) is an example of a young person employing the strategy of 'being present' to access information and simultaneously to support other family members.

SK: Chloe, you said that at the beginning, Lynn mentioned that you wanted to be there- this might seem like a daft question, but could you explain why?

Chloe: Because I woke up and Lynn (*her dad's wife*) told me: 'don't panic, Chloe, but your dad's in hospital, he's got a brain haemorrhage.' And I was like - really ill with tonsillitis and I was in bed half asleep. And she was crying so I was crying and she said 'bye' and I put down the phone. And I woke up a bit and I was just like - panicked, you know, I didn't know whether to call back and (.4) I mean, she said brain haemorrhage, and then I talked to mum and she like explained to me exactly what was going on and I said, of course I want to see dad and also be with Lynn, just because it's my dad (.2) you know what I mean? And he was going to (study hospital) and I just - (.4) I think if Kara (*her mother*) had said to me: 'you know, you should stay in bed', I'd have said: 'No way! That's my dad. I have to be there for him, I have to go in.' It's my dad and I love him, you know what I mean, and obviously I'm going to want to go to be with him and be there for him.

At the time of the incident Chloe was ill and not feeling well. Chloe clearly reflected on the term 'brain haemorrhage' and understood the seriousness of the situation. Her love for her father triggered her need to be near her dad and 'be there for him' at a time of uncertainty. Yet, at the same time she explained that it was not just her dad, Phil,

she wanted to support but also Lynn, his wife. Chloe's motivation and the difficulties she faced in supporting Lynn as well as her father become even more significant if the family conflict in the background of this family is considered. This family was an example of what I have termed 'families-within-family' (see Chapter 5). Lynn, for example, was not part of Phil's family of origin. Chloe's definition of her family, however, included Lynn and she stressed this several times during the interview. She had drawn clear boundaries around her family enabling her to act on her need to support another family member. In being clear on who was part of her family, Chloe took control of her experience with critical illness and co-constructed the experience of others in her family.

It is not a new insight that 'teenagers' in particular feel a greater responsibility towards other family members at a time of illness (e.g. Titler et al. 1991, Craft et al. 1993). Illness as such challenges role functions within families (Johnson et al. 1995). Taking on the role and functions of the ill family member increases the workload of the healthy parent considerably (Hupcey and Penrod 2000). Fay (12, family 3) commented that her mother 'has a lot of responsibilities just now on her shoulders' suggesting that young people recognised the increased burden on the healthy parent. Children deliberately and purposefully attempted to support their healthy parent. This became evident when parents reported that their children 'were better behaved' and 'quarrelled less'. Younger children also took on a number of household chores unasked in an attempt to support their parent. Older children, like Ewan (15) focused in addition on psychological support for the parent.

Ewan: I wasn't here the weekend. I was staying at my brother's. I wish I was here.

SK: What would have been different if you had been here?

Ewan: I would have been here for my mum. It would have made me feel better, knowing what was going on. []

Ewan was aware that he could not have done anything for Graham at this stage. But, as he argued, he could have been there for his mother and it troubled him that he had not been home. Ewan phoned his mother during the day on a regular basis to reassure

himself that ‘she was alright’. When this family was asked who suffered the most, Ewan answered without any hesitations that it was his mother. Pam, his mother, was rather taken aback by this. The psychological support young people like Ewan or Chloe and others offered was based on their understanding as reciprocal equals within their family units. By ‘being present’ for their family members, they went beyond their own need to access information by considering other family members needs simultaneously to their own and acting accordingly. This is an example of what James and Prout refer to when they argue that:

‘children are and must be seen as active in the construction and determination of their own lives, the lives of those around them and of the societies in which they live’(James and Prout 1997:8).

A further strategy to access information was that of ‘direct and indirect questioning’. This strategy emerged in families where young people suspected adults were withholding information.

Young people accessing information: direct and indirect questioning

In some families the circumstances of the accident were such that a different adult than a parent had to inform a young person of the developing crisis. This situation emerged in families where either child or parent was somewhere else when the family was informed about the accident or pending ICU admission.

At times this was a close family friend or a step-parent or a grandparent. These adults were required to judge what they could and should tell a young person and what might be best left for a parent to explain.

The experiences of family 3 can serve as an example. Julie, the mother, was travelling on business when Peter, her husband, had an accident. Phil (4), Mona (10) and Fay (12) were used to the absence of one or both parents due to their business travels. During these times Louise, Julie’s mother, would look after the children. She was the adult who had to tell the children that their dad had had a serious accident and had been admitted to ICU.

During our pre-interview conversation it emerged that Louise had been very vague in her information to the children. She had also made the decision to withhold Peter's critical illness from Phil (4) altogether. In order to explain his dad's absence, Louise had told Phil that 'dad was in (name of city)'. Phil associated this particular city with his dad working there for a period of time before coming home. It became clear in the pre-interview conversation that Julie would have preferred to tell Phil the truth or at least tell him 'that dad was sick and in hospital'. Julie did plan to tell Phil the truth but once this 'white lie' had been told, it was difficult not only to find the right moment but also what to tell him - in particular because Peter's survival was not certain.

Louise, as a grandparent, adopted the same protective behaviour towards her grandchildren as I discussed in Chapter 6 in reference to parents. She had told Fay (12) and Mona (10) that their dad was 'really, really ill' but had not defined what this entailed. Peter had suffered a serious head injury while falling on stone and was in a coma. When I asked Julie if she thought that the girls had understood the meaning of Louise's comment, she answered 'no, I don't think so' and offered the following incident as example for her belief. Mona had been due to leave on a three-day school trip. It was left to her to decide if she wanted to go. She finally decided to participate despite Peter's situation. After learning about Mona's decision Louise asked her to reconsider reiterating that her 'dad was really, really ill.' While being vague attempts to protect children from the stresses of critical illness, it also leads to a situation where young people lack necessary information to understand what is going on or to make an informed decision. A number of authors (e.g. Lewandowski 1992, Clarke and Harrison 2001, Dale and Altschuler 2006) argue that the failure to inform children is misguided. 'Being vague', even though Louise had the best intentions to protect her grandchildren, can be seen as a form of misinformation which actively prevents young people from understanding what is really going on.

In this light, excluding younger children like Phil (4) can cause problems in the long run. The underlying adult assumption is that young children do not notice that something is wrong. As has been discussed earlier in this thesis, critical illness has such a profound effect on daily life routines that even young children notice changes. How could they not? Landau (1997) points out that secrecy is always potentially

destructive and that children do have a sense of what is happening. What differs is their ability to ask the 'right' question (Lewandowski 1992). This view is supported by Phil's reaction in constantly and repeatedly asking 'where is daddy?' While Julie was unsure whether Phil 'knew something was wrong', both Mona and Fay were convinced he did know. Phil had asked every member in the family available to him where daddy was and 'when does daddy come home?' It was interesting to learn that Fay and Mona adopted and observed Phil's exclusion by calling their dad 'Billy Joe' and reiterating that 'daddy was in (name of city)'. Inventing a pseudonym for Peter enabled both girls to ask Julie questions about Peter's current status in Phil's presence.

It was however Fay's (12) way of questioning her mother during the interview that alerted me to the strategy of 'direct and indirect questioning.' Fay was suspicious about the 'quality' of information she received from adults. Quality in this context refers to clear, understandable explanations about what was happening rather than just being told that 'dad is really, really ill'. She was clearly looking for understanding and meaning. This became evident when she started indirectly questioning her mother about Peter's situation.

Fay (12): Mum. Do you know the woman that won't wake up?

Julie: Mhmm. (*nodding*)

Fay: Well (.4) was she (.5) did she wake up?

Julie: Mhmm.

Fay: And she went to the other ward now?

Julie: Mhmm. (*confirmative*)

Peter had been in the unit for almost two weeks and had made very little progress. Fay very skilfully used another patient in a similar situation in ICU as an example in comparing her dad's situation with this female patient. She is looking here for clues from Julie to get an idea as to what the future might hold. Julie however only indicates that she knew which patient Fay meant without revealing any further information on Peter's prospects. At that point Fay did not probe any further and seemed to accept her mother's reluctance to come forward with any information.

In my experience interviewing families with younger children is a 'moving affair'. This is not only because younger children jump in interviews from one issue to the next but also because they are literally moving around and doing other things (i.e. eating, getting something to drink, answering the phone, moving places etc.) while being interviewed. This 'movement' happened here too and it was some time later in the interview before Fay renewed her attempt to get information from her mother. This time however, she took the direct route.

Fay (12): Actually mum, what's got dad wrong with him?/

Mona:/ I smashed the clock.

Fay: What's got dad wrong with him?

Mona: Yeh, I want to know that too.

Fay: What has he actually got wrong with him?

Julie: We don't really know – he is, he is heavily sedated (.3) well, they're trying to keep his brain quiet.

Fay's earlier reaction might suggest that she had accepted her mother's reluctance to come forward with information. The second excerpt however implies that she was clearly fishing for information. In her choice of words and persistence she underlined not only her need for information but also that in her view she was 'actually' entitled to information.

Mona, who appeared to have a simultaneous but different conversation at the time, was in actual fact very attentive and listened closely to Fay and her mother's interaction. This becomes evident when she chipped in with her sister asking for information, increasing the pressure on Julie to come forward. Julie however was again reluctant to address the seriousness of the situation. As I argued in Chapter 6, adults withheld information not only to shield children from the impact of critical illness but also to buy the time they needed to cope with the uncertainty attached to the situation: when I asked Julie how she was coping with the situation she answered 'barely'.

In a situation where there was a high level of clinical uncertainty it was very difficult for parents to know what to tell their children. Clive (family 4) stressed this issue in saying that ‘they didn’t know what to tell the kids ‘cause we had no guarantees either.’ Julie too understood Fay’s need for information. She revealed in our pre-interview conversation that she ‘thinks Fay is looking for information’. Yet, a high level of clinical uncertainty made it difficult for both families to include young people to an extent that an understanding of the situation could follow. ‘Not knowing what to tell the kids’ is in contrast to nurses’ expectations that parent would prepare children for an ICU visit since they literally did not know what to tell (see below). It is at this point that the lack of appropriate information material (Vint 2005a, 2005b) was most keenly felt by parents.

Tied in with the absence of information material for young children is their understanding of ICU on either a concrete or abstract level, which in turn is influenced by their age and prior experiences with illness.

Understanding the ICU: environment or function

Understanding critical illness and therefore the ICU is directly linked with the ability of a young person to look for clues, interpret theories and draw conclusions in terms of outcome possibilities. Cognitive maturity of a child but also prior experiences played an important role in this context. Two different levels of understanding emerged from young people’s data. Younger children tend to understand the ICU on a concrete level, which was evident in their focus on ‘ICU as environment’. Older children or children with a prior ICU experience in their family understood the ICU on an abstract level which was evident in their focus on ‘ICU as function’.

ICU as environment

That younger children tend to focus on ‘ICU as environment’ is nicely illustrated in the following Focus Group excerpt. Earlier I had asked nurses if they encourage children to visit their critically ill family member. The discussion then evolved around different reactions from younger children as opposed to teenagers (to use the terms used by nurses). One of the nurses recalled a younger child who used to visit her Granny and ‘lent the nurses a helping hand.’

E3: I mean we had that young kid. You remember the girl that used to come in and help?/

E1: /yeh, down at bed 7. I used to give her gloves/

E3: /and she used to go to the bed and follow you around, it was her granny, and she felt that she was a big girl, you know. (*Laughs from the group while the two nurses recall the experience*)

E1: Yes, I know she came and 'helped', she washed her granny's face with me and washed her hands.

SK: And she asked you for aprons and gloves?

E1: She wanted (*laughter from group*)- and she was following me round the bed, she was asking me quite happily: 'what are you doing this for?'

E3: Asking about your charts.

E1: Yeh.

SK: So, they enquire more?

E1: Mhmm. (*confirmative*) They are very inquisitive.

E2: Oh yeh, aha.

E1: And she was quite comfortable. I think she was probably a very self confident little girl anyway.

E3: Mhmm, I think so - yeh.

SK: And do you think she actually ever thought why granny was there, or is that more, oh it's quite exciting granny is here?

E1: I think she was more, I think she was more interested in doing things for granny rather than sort of /

E3: /why she was here/

E1: /talking about why she was there.

It was not uncommon for nurses to 'include' younger children in some of their nursing tasks. Writing down observational data, helping to wash a patient's face or creaming their hands were some of the examples given by participating children as well as ICU nurses. ICU nurses perceived younger children as being more inquisitive compared to

teenagers. As pointed out earlier, nurses attempted to engage younger children in a 'game like' (S1) approach to understanding using their curiosity as drive to explain surrounding medical technology. What was interesting to realise is that the emotional work required by ICU nurses while working with young children or teenagers differed considerably. Relating to younger, and possibly inquiring, children was for most nurses not a problem. In one focus group nurses described their approach to younger children as:

D3: It's more of a jovial sort of- [] a jovial approach for sort of kids under 10 and sort of making balloons out of gloves. (*Group agreement: mhmm*) And they're allowed to touch a lot more things/

D1: /getting the stethoscope/

D3: /yeh and sort of playing with things. Whereas with the older children, it's more of an open mature approach and you ask if they have any questions. Whereas with a five year old you probably wouldn't start the conversation: 'do you have any questions?' to a five year old (*group: laughter and yes*) as they walk in the door. You just blow the balloons and () and play and all. They usually just scream and shout: 'what's that, what's that' and you can tell them really it's () (*group laughter*), you know what I mean. You wouldn't obviously like- take fun out of them, but you probably wouldn't give them all of the information, sort of thing. []

Nurses in different focus groups confirmed this 'game like approach' (S1) to younger children and accepted their 'help' (F2) writing down observational notes or helping to 'wash granny's face' (E1).

This ties in with an observation made by Dale and Altschuler (2006) pointing out that since society portrays childhood as a protective space parents and professionals avoid discussions which challenges that protection. Thus, younger children who had not necessarily made the link between critical illness and any possible health outcomes, including death, were not challenged by adults. They were left in their 'unknowing' curiosity to explore 'ICU as environment' and nurses were happy and forthcoming explaining what the surrounding technology was for and why they were doing certain things. Through playing with medical equipment even young preschool children (aged 3 – 5) are able to understand what things are for (McGrath and Huff 2001). This finding is supported by, albeit older, children in my study where young people had at

times the opportunity to ‘try out’ certain things. Fay (12), for example, tried a pulse oximetry probe on herself.

Fay: I got to try an oxygen thing. (*Oximetry probe*)

SK: Oh, did you?

Fay: Yep.

Mona: Lucky you. I didn’t!

Fay: I got 98 percent oxygen.

SK: Mhmm.

Fay: And he had (*her father*), he had a 100 - but it’s been going down. It was 99 and then 98.

It was evident in the interview that Fay had understood what the probe was measuring. Understanding why it is necessary to measure something is, however, a different issue. In comparing her peripheral oxygen values with those of her father’s, Fay draws attention to this fact. What was her understanding of her observation? Her tone of voice suggested that she found comfort in the fact that her father’s oxygen levels were similar to her own. Fay accepted the readings at face value not making the connection between her father’s brain injury, his need for ventilation on high oxygen levels and her normal oxygen saturation value. A real understanding of her observation consequently did not follow. I have already presented data in which the interest of children in medical technology is evident. The level of interest remained however on a superficial level in that necessity of why something is happening was not questioned by children and consequently not addressed by adults. This, in turn, impacts on children’s understanding and is an example of children understanding ‘ICU as environment’ as opposed to ‘ICU as function’.

What the above nurses’ excerpt also implies is the way in which young people shape their own experiences. Nurses followed the lead of a child in answering their questions. This allowed nurses to focus on environmental issues since this was what younger children tend to ask about, leaving any issues of health outcome or

implications of a critical illness for parents to address. The pre-requisite however is a questioning child - but not all young people ask questions. I asked also Emily (8) and Connor (11) about their first time in ICU. As pointed out earlier their recollection was focussed on environmental details. Emily was one of the 'inquisitive children' nurses referred to in the above excerpt. She was confident and happy to ask questions about her surroundings. Connor (11) however was different.

SK: How was it for you Connor? Did someone explain/

Connor: /No./

SK: /to you what the stuff is?

Emily: The only reason someone explained it to me was because me and mum were asking what all the things were.

SK: Right. And you didn't ask them? (*Towards Connor*)

Connor: No.

It became evident during the interview that not asking questions had an impact on Connor's understanding. While Emily had described in some detail what she had seen and could explain some of the functions or purposes (e.g. bio bag collected stuff out of dad's tummy, machines monitor heart rate and temperature) Connor relied on his own imagination at times in order to understand what things were for.

Connor: I just saw, like some monitor-rhythms and bags hanging on the bed and/

Emily: You didn't see the bio bag?

Connor: No, I saw the other bag.

SK: Which other bag?

Connor: The urine (*hesitantly*).

SK: Oh yes, from the catheter.

Connor: The sperm.

Connor just had had sex education at school. He therefore constructed an understanding incorporating his observation with something he had learned at school.

His belief that the urine bag must contain sperm because the catheter is inserted through the penis became evident during the family discussion between Sarah (his mother) and him following his revelation. While this is an amusing example, the implications are not. Within this scenario there is the serious danger that quiet young people will have misunderstandings which exacerbate an already stressful situation. As pointed out earlier, nurses did not necessarily pick up on quiet young people's need for information. In reference to younger children there was the belief amongst nurses that:

D 1: [I think] if you support the parent, so that they are feeling reasonably comfortable, they will then be able to comfort the child. So, although we are going to be comforting the child and the parent as well, but, you know, like the initial things, making sure that the parent is happy and reasonably comfortable and so they then introduce the child. (*to ICU*)

The same belief was reiterated in another focus group:

E3: I think if families are prepared to take younger kids in - I think they are going to sit there and say to them: 'they've got a tube in their mouth', you know, and I think we're more likely to then say something. Whereas if you've got a teenager coming in - I think that maybe- I don't know if it's me that's thinking this, I don't know whether that's kids or not - ahm but whether that is explained to them the same way as it would be to a younger child I think it's probably explained by families more step-by-step with the younger child.

Group: *Mhmms*

Clinical uncertainty and the lack of knowledge about the ICU environment made it difficult for parents to know how to prepare and what to tell their children. Clive's (family 4) earlier comment that 'they didn't know what to tell the kids 'cause we had no guarantees either' supports this view.

While younger children saw their parent 'all wired up' (Emily) and were curious about the environment, older children looked beyond ICU technology and focused on 'ICU as function'. I have already presented some data in this chapter in which nurses expressed their belief that young people in their teenage years have different information needs. This particular belief was based on their observation of young people's reactions and questions within the ICU setting.

ICU as function

Accounts from nurses in all focus groups indicated that nurses went out to meet young people in their teenage years in the unit's waiting area before they visited someone in ICU. Nurses perceived this particular age group as having 'more of a perception' of critical illness and therefore assumed a different level of understanding.

This perceived difference in understanding was emphasised across focus group discussions. Prior to the following excerpt nurses had discussed the influence of television programmes (i.e. ER, Casualty or Holby City) on young people's expectations and understanding of ICU. I had asked if this reflected the nurses' belief or why they thought TV programmes influenced a young person's experience in ICU.

E3: But you do see them if there're in the unit when alarms do go off they do, they do, sort of stand back and get a fright /

E1: yeh/

E3: /and there is that difference between being a () visitor, they are more aware and- You know, if there are alarms, you know, they ask: is that o.k.? What is that and what is that, why is it doing that?' sort of thing, so I always pre-warn them before they come in because they are a bit more jumpy and a bit more aware of their surroundings.

SK: What do you warn them about?

E3: Ventilators, alarms going off, probably more from temperamental machinery rather than, you know, it meaning anything. A lead has fallen off or you know, this kind of thing. Ahm, monitors, cables, the tubes, just basically everything that's sort of attached to them going on, and they're not just going to be lying in a bed with an oxygen mask on, there's more going on.

While it became apparent in the resulting discussion that nurses believed that there was a link between hospital drama programmes on TV and behavioural responses of young people, what is of interest here and is obvious in the above excerpt was the difference between young people's understanding and interpretation of surrounding technologies and their functions and that of younger children. Questions like 'is that O.K.?' or 'what is that?' and 'why is it doing that?' are indicative of an insight beyond the mere presence of technology. This type of questioning aims at gathering information to understand the present situation but also seeks reassurance that their family member's

status is monitored for his or her safety. It also implies the expectation that any concerning measurements or alarms are acted upon.

A case in point was Emily (8, family 7) and Connor's (11) discussion of the ventilator's alarm function. Discussing their experiences when visiting their father, Emily had casually mentioned that 'they turn the alarms off'. At this point in the interview Connor looked at Emily and contradicted her in saying 'no they don't!' He was clearly distressed at the possibility that nurses could turn machinery alarms off. Connor's reaction suggested that he did not know that alarms could be suppressed for a defined time without being turned off. Emily's account of the event suggested that the alarm went off due to 'temperamental equipment' rather than there being a real problem at the time. Sarah, their mother, needed to reassure Connor that 'nurses would not turn off alarms' before he would calm down again.

This example underlines a difference in understanding. For Emily, the ventilator was of 'environmental' interest; a piece of equipment, which alarms from time to time and nurses 'turn off' on occasion. Connor, in contrast, had made the link between the equipment's alarm function and something not being right. Connor understood the alarm function as part of his father's monitoring. The reason why he was so upset about Emily's story is linked to his constructed meaning of alarms, namely the indication that something was going wrong. This in turn should trigger any necessary interventions to safeguard his father's well-being as opposed to 'alarms being turned off.' Connor's understanding is focussing on 'function' while Emily's interests remain in 'environment'.

It is these kinds of young people's anxieties nurses were discussing in the above excerpt. Nurses linked their observation of alarms going off and 'jumpy' or 'frightened looking' teenagers and interpreted this understanding as young people linking alarms with the concern for family members' well-being. Their belief of teenagers having 'more of a perception' of what critical illness means was based on behavioural observations and questions they asked. In proactively pre-warning them and explaining to a young person what they would see and possibly hear in ICU, nurses aimed to support and reassure the visiting teenager.

I was therefore particularly interested in how nurses prepared young people before going into ICU. Another focus group offered the following insight.

F3: Various ways. It depends if they've been into ICU before () we go out. We tend to find out if they've arrived, we go out and speak to them, often briefly at first 'cause it usually coincides with the patient arriving on the unit. (.2) Ahm, then I would tend to go out and sit with them and describe what they're going to see in intensive care, the patient's condition.

We also have photographs of patients in ICU that we can take out. We often use them for younger people and children to show them exactly what their relative is going to look like ahm and get them to ask any questions before they go in. And then go with them in because it's often a shock just seeing the relative for the first time, and speak to them again then.

SK: But then you try and focus on the patient's condition rather than say: oh, yes that's a monitor I showed you?

F1: Yeh. []

F2: Some less experienced nurses sometimes launch into the equipment rather than the patient and that's where we come in and try and steer them a little bit.

The above excerpt draws attention to nurses' experience and its role in information giving. The focus of information and subsequent support shifted from environmental to situational issues. This particular difference, which is linked to emotional work of ICU nurses, will be addressed in more detail in Chapter 8.

The above quotation underlines the nursing practice at the study site, namely preparing a young person prior to entering the unit. What is of particular interest is the nurses' understanding that it is 'often a shock just seeing the relatives for the first time' in ICU and that therefore accompanying young people into the unit is good nursing practice.

Young people in this study support this view. Ewan's (15, family 1), for example, said that:

The first time I had seen him with all the machinery, ahm, oh - it was a wee bit scary. The first time I had seen him.

The accounts of most young people in this study indicate feelings of ‘being shocked’ or ‘scared’ while seeing their family member for the first time in ICU. At times the arrival of a patient coincided with that of family members. In this situation nurses did not always have time for a conversation prior to the young person seeing his or her parent. Chloe’s (18) experience of seeing her father for the first time, unprepared, might serve as an example here:

Chloe: Yeh, the first time I saw dad, he’d come round the (.3) sorry, the hall (.10 – *pause due to trying to remember events*) you know, he’d just got this thing in his head and they wheeled him past and that was horrific. I went-

Lynn: You realised-

Chloe: Yeh, I went hysterical.

Lynn: Yes.

Chloe: Yes, because that was the first- you know, the last time I saw him he was like my dad and then he’s lying there on a bed with all these wires and stuff. And I got really hysterical and remember we were waiting to see him? (*towards Lynn*) And the first view was just a nightmare. It was a nightmare, it was just like, going in to see him just lying there. He was like a dead weight, and he was under so much sedation then. All these wires coming out, you know, it was just- it was the worst day, wasn’t it?

Lynn: Mhmm.

Chloe knew at the time that her father was admitted due to a brain haemorrhage of unclear origin. Her need to ‘be there’ was related to her understanding that this was potentially a life-threatening situation. It is evident in her account that whatever she had expected was not what she encountered. In describing her experience as a ‘nightmare’ Chloe’s shock at seeing Phil becomes apparent. It is of interest to note that it was not just ‘all these wires coming out’ but also the fact that Phil was ‘like a dead weight’ that contributed to her anxiety. While she understood that this was a result of sedation, her expressed anxiety was linked to the level of clinical uncertainty at the time. Clinical uncertainty in this context refers to Phil’s survival but also to the possibility that he might have suffered some degree of brain damage. In becoming ‘hysterical’ her high anxiety levels and her beginning realisation of how seriously ill her father really was are evident in her account. In linking Phil’s need for intensive

care, Chloe understood ICU as function. Function in this context is viewed as focusing on preserving lives. What Chloe's experience also underlines is the importance of preparing young people for what they might see and hear before seeing their critically ill family member for the first time (Craft et al. 1993).

The unresponsiveness of patients was a major concern for many young people. Anna (16, family 6) offered a very similar insight to Chloe on this issue.

Anna: It was just like, for a wee bit, like my dad isn't normal and just seeing him, like sleeping, you know, it just wasn't him at all. And to have all these things round about and things he didn't- (.3) and he'd just be lying there with a tube in his mouth and it wasn't very nice.

Anna knew that her father had suffered a 'brain incident'. Clinical uncertainty at the time referred to the absence of an exact diagnosis and the unknown outcome. The unresponsiveness of Dave, her father, felt to Anna 'like my dad isn't normal'. Similar to Chloe, Anna linked her knowledge of her father's brain related illness with that of her observation of Dave in ICU as environment in constructing meaning of the situation. Her functional view of ICU transpired when she commented that:

'It was just because he had like (.2) that many things round him, all the machines. It was actually, we were very struck by how amazing it is as well, for those kind of machines and stuff would keep somebody, like going, you know.'

Anna linked her father's critical illness with ICU as environment and interpreted the function of ICU as a means to preserve life. She was well aware that medical technology is playing a major part in this effort pointing out that 'for those kind of machines and stuff would keep somebody going'.

Awareness of medical technology was part of young people's understanding of ICU as function. Technological awareness, in this context, goes beyond the technology itself and includes an idea of why it was needed at that time of critical illness. Shocking though the amount of technology was to see for the first time, it was nevertheless understood as being part of safeguarding their family member's lives.

A further aspect of young people's understanding of ICU was related to the nurse-patient ratio. This aspect has two dimensions. One is related to feeling that the family

member was safe in ICU while the second dimension is concerned with nurses' competence.

Anna (16, family 6) had raised this issue in particular. Originally, her father had been admitted to HDU before being transferred to ICU and then, at the time of the interview, back to HDU. I had asked her what she thought the difference was between ICU and HDU. She answered:

'I feel as well (.3) in intensive care you are – (.4) not that it's more better or anything, but it's just that I felt that he'd be in more care if he was in there, obviously because that's what's- (.2) it's more staff.

[]

But the high dependency unit is more like normal wards and ah (.3) to me he doesn't feel that if he would be safe (.2) but he is. [] Although when my dad was actually taken back to the high dependency unit it was like a step back – it's like.'

Similar to Anna, Ewan (family 1) and Chloe (family 9) commented on the high nurse-patient ratio which meant close monitoring of patients which in turn contributed to their feeling that their family member was safe. Anna's comment that Dave's transfer to HDU 'was like a step back' has to be understood in this context. HDU patients are not as closely monitored as ICU patients. This interpretation is supported by her later comment that HDU also meant that 'he is a step closer to home.' In essence, her feelings were ambivalent. On the one hand she would have preferred the 'safety' of an ICU environment on the other hand she understood that HDU was a step in the right direction for recovery.

The second dimension of the nurse-patient ratio aspect was related to young people's perception of nurses. In the interviews they spoke about their impression that nurses seemed to 'care for' the sick family member. Ewan (15, family 1), for example, compared the care Graham had received in the transferring hospital and the study site. Graham had some dried blood on his mouth, which had only been cleaned up after being transferred to the study site. It was these kinds of little things young people saw, which let to their assessment that someone was cared for.

Young people commented on their observation that nurses seemed ‘competent’ (Anna; family 6; Chloe, family 9) in what they were doing or that they were ‘knowing what they were doing’ (Chloe, family 9; Shona, family 5). Nurses were praised for ‘being fantastic’ or ‘really good’ (Ewan, family 1; Fay, family 3; Shona, family 5; Jody, family 7) with their ill family member as well as with the rest of the family.

The above data demonstrate the difference in understanding critical illness and ICU. Younger children tend to view ‘ICU as environment’ and understanding was on a concrete level. This group of children lacked the maturity to link the need of ICU and its technology with the seriousness of the patient’s situation. Consequently, any outcome possibilities were not part of their understanding. Nevertheless, they were very ‘curious’ and ‘inquisitive’ about the environment and keen to ‘help nurses’ in caring for their ill family member. Information needs of these children reflected their understanding in predominantly focusing on environmental issues.

Older children or children with a prior ICU experience in their family understood ICU on an abstract level which was highlighted in their focus on ‘ICU as function’. This group of young people had the maturity and ability to look for clues, interpret them and draw conclusions in terms of outcome possibilities.

Summary

In summary, the presented data reveal that how young people experience critical illness in their families is influenced by their embeddedness in their generational position. Adults, in the form of parents and nurses, were gatekeepers to the information children wanted and their access to information was influenced by the perception those adults held of young people. As such, parents deliberately controlled the content, timing and who was giving the information. These parental strategies aimed mainly at protecting and shielding young people from the stresses of critical illness.

Despite power asymmetries in families, young people were not passive but rather actively constructed and co-constructed their own as well as other’s experiences during a time of critical illness. Children’s agency and therefore their temporary and partial

separability from carers, communities or culture enabled them to act upon their own interests. This was evident in the many strategies young people employed in ‘keeping normality in their lives’ as well as accessing information.

In this context, being able to visit someone in ICU was an important means to access information. At the same time, visiting a family member in ICU is not equivalent to actual understanding. In fact, younger children focused on the ICU as environment and not necessarily on its function in supporting life during a life threatening illness. Other children also had an understanding of the ICU function in the sense that the outcome was uncertain.

These different levels of understanding are of importance since they explain and are reflected in the different dimensions of ‘fishing for information.’ A younger child, focusing on the ICU as environment and therefore predominately on surrounding medical technology, is simply demonstrating his or her level of understanding. This particular child needs a different level of support and information to understand the wider implications of critical illness and outcome possibilities compared to an older child.

Older children made the link between critical illness and the ICU as function. They understood the life supporting function of the ICU and were well aware of outcome uncertainty. It was not surprising that nurses identified this group of young people as being in need of more support and information. Young people’s strategies of positioning themselves are indicative of their need to be included in the critical illness situation: only then can understanding and coping follow.

Finally, including young people in the critical illness situation is crucial to supporting them through a time of uncertainty. Parents and nurses need to reflect on young peoples’ ability and right to participation by being open and honest with children of all ages, but in a manner appropriate to their age. In the next chapter nurses’ experiences with families in ICU are the focus of analysis.

CHAPTER 8

Nursing in Public: Intensive Care Nurses' Experiences with Families

Introduction

In this chapter I present my findings relating to ICU nurses' experiences with families. 'Nursing in public' emerged as an overarching theme under which ICU nurses discussed their experiences with families. From a nursing perspective, the ICU is very much understood as their 'turf' (Heimer and Staffen 1998) and experiences with families emerged particularly around issues related to an open visiting policy. The impact of this policy on nurses and nursing is evident in a number of areas relating to nurses' control over their working time, adherence to unit rules, emotional management and the increased need for negotiation.

In listening to families and nurses it became apparent that both groups are part of different worlds in the same social space - the ICU. It is for this reason that I set the scene by presenting families' perspectives before linking this 'outsider' perspective with nurses' views and experiences with families in the ICU.

Intensive care unit: one space - two worlds

Moonscape: the surgical intensive care unit

The first impact is like finding oneself on the moon, or a planet, light years away from the dissatisfactions and delights of everyday life. Everything is strange, different. The landscape is unrecognizable. The rules are dissimilar. It even smells different. (Cassell 2005:1)

Cassell, an anthropologist, captures the bizarre strangeness of the technological, life supporting, intensive care world. A world organised around its own rules and language in which outsiders easily can get lost. Families enter this 'deeply weird' (Cassell 2005) world of intensive care when a family member is admitted. In listening to families and nurses I realised over time that the 'outsider' perspective of families is

an important part of ICU nurses' experiences with families. For nurses, as Chambliss points out, 'the hospital is a normal place, and with routinization even traumatic events that occur there appear normal' (Chambliss 1996:61). While caring for critically ill patients is what ICU nurses do on a daily basis, having a family member in such a unit is, in contrast, an extraordinary event in a family's life. It is not surprising that families and nurses inhabit different worlds in the same social space.

ICU environment

In Chapter 6 I pointed out the stresses and strains family members experience at the onset of critical illness. In entering the intensive care world, families came into a world with an unrecognisable landscape, dissimilar rules to those in their everyday lives and a language of its own. The environment is full of machines with different sounds, beeps and buzzes that need interpretation (e.g. Carnevale 1991, Chesla 1996, Phillips and Barnsteiner 2005). Distinguishing visible and audible alarms and their significance is part of nurses' routine working knowledge but this knowledge is something families understandably lack. The family's attempt to understand what was going on resulted at times in focusing on technology.

Andrew (family 5): [] And then (.2) we kept watching this little monitor because they said we want to keep him below 35 (*refers to ICP*).

Shona: We were watching his ICP all the time.

This family understood the importance of managing Hamish's ICP values (see Chapter 6) and were anxiously observing it. More generally, nurses understood that there was a link between families watching monitors and their search for clues to patients' conditions.

F3: Which they often do, you know, that's figures they can relate to and everything, and it's actually very tense working then because they're (*inhales*): 'that's up again! It's up to 25 again (*refers to ICP*), what are you going to do about it?' (.2) So it's nice to- so they know what's happening but they're not totally focused on all the numbers. (*Group agreement: mhmms, yehs*)

F1: Because sometimes the numbers don't mean- (.2) they mean something else, they mean you've just suctioned the person or you've moved them or something, they don't always mean that it's a sort of - yes, you've got to react to it.

Nursing under constant observation and having their reactions towards ever changing monitoring data and alarms questioned could create tense working conditions. Naturally, sounding alarms had an impact on family members and nurses across focus groups described family members' reactions as 'jumpy' or 'worried' (E2, D&E1) when alarms did go off. This was one reason why nurses warned visitors of 'temperamental equipment' and 'the going off of alarms' (D3, E3, F2) before they entered the unit. For family members, intensive care is not only an unexpectedly noisy environment but also one where time is needed to learn to read nurses' reactions towards alarms. As one of the nurses in the above excerpt points out a sounding alarm does not always mean 'you've got to react to it.' In the event of an emergency nurses reacted calmly, asking family members to leave the unit.

F1: And if something happens. I find if you just say to the relatives, you know: 'If you just give us a minute, someone will come out and explain to you what's happening, but if you just step out just for a minute while we sort this out.' Even if it's something really acute, you know, if you try to, sort of say: 'if you just want to step out. We will come out and see you in a few minutes and let you know.'

This calm request to leave the unit 'just for a minute' is a markedly different reaction towards alarms that needed immediate intervention than families expected to see. Many family members commented on how calm nurses were when a situation arose which required immediate attention. Linda (family 5), for instance, remarked that the nurses 'never looked flustered, they stayed so calm and it was so reassuring.' Nurses argued that staying calm ensured calm family members and thus this was a strategy to create the focus and time needed by staff to attend to an arising emergency. While this was a very effective strategy in reassuring family members, it also had a delaying effect on a family's understanding of the seriousness of an incident. Some families commented for example that 'I didn't realise that it was actually touch and go' or 'we didn't think at that point that they didn't think he'd survive.' In this sense, staying calm had a functional gain for nurses in that the unit's atmosphere remained calm and therefore allowed them to focus on the emergency as opposed to 'hysterical family members.'

Medical language

The strangeness of intensive care is further manifested through a different language. The use of any professional language has the potential to distance and to function as a barrier to inclusion and understanding. Family members' pre-conceptions of intensive care and its professional language interfered at times with the 'right' interpretation and with the conclusion drawn. Beth's (family 2) experience is a telling example.

Beth: And I am thinking 'he is not on a life support machine.' I thought 'no, he's on a ventilator, so he's not on a life support machine, that was my next -/

Ross:/ Yes, but there is no such thing as a life support machine.

[]

Beth: I mean, for crying out loud, you know. You just don't understand the, the terminology for a start! So, how you get that – I don't know how you'd get that across to people, the terminology is all wrong.

Beth had heard the term 'life support machine' in everyday conversations while health care professionals used the term 'ventilator'. Both Ross and Beth discussed and agreed that terms like 'life support machines' were used by lay people when they actually meant ventilators. Realising this after the exposure to intensive care did not alter the confusion Beth and others experienced when confronted with the appropriate medical terms. In this case, Beth's assessment of Brian's situation was influenced by her assumptions about 'life support machines'. Her understanding was that Brian was certainly critically ill but not life threateningly ill since he was on a ventilator and not on a life support machine. In realising that 'life support machine' was the lay term for ventilator she was forced to reassess her understanding of Brian's situation.

While using a specialised language is effective for communication among health care professions it also excludes outsiders. This became apparent in family 5 where Shona (20), a medical student, had very different conversations with physicians than her parents did. In fact, her parents felt excluded at times.

Andrew: They were talking to you! Not to us.

Linda: (*towards Shona*) It was quite obvious that you were far more intelligent than we were and apart from – (.2) the second consultant ended up looking at you and talking to you all the time (*laughs*).

Shona: Because/

Linda: / Because the questions she asked (*towards SK*) – it was obvious from the questions she asked that she knew something what she was talking about. [] They gave her more detail than probably they would have given me. Maybe not. I think.
[]

Andrew: It is the same language.

Linda: Mhmm. (*confirmative*). They speak the same language.

Linda and Andrew as Hamish's parents were ambivalent about their exclusion. On the one hand, it was Shona's specific medical knowledge that enabled her to ask more detailed questions, putting her in a position to explain to her parents what was going on. This had an impact on the quantity but also, as Linda points out, the quality of information this family received since Shona was given 'more detail'. On the other hand, Linda and Andrew were Hamish's parents. Their ambivalent feelings about their partial exclusion implied that they expected to be the addressees of the information and crucially that the amount and quality of information they received should not have depended on their professional background. This is not to say that physicians failed to explain or give information but rather that there was a marked difference between this family and their, or Shona's, communications with physicians and other families in this study. This observation is in line with Strong's (1979) argument that family members within medical disciplines are treated differently by physicians and, crucially, within the rules of the medical bureaucracy. Strong asserts that in his study 'the majority of the medically-qualified parents observed the standard rules with some care' in not challenging the authority of treating physicians (Strong 1979:96). It appears that in Shona's case, her status as a medical student allowed her to ask a number of questions which enabled consultants to relay information in a teaching format. Thus their expertise was called upon, it was never questioned.

The other interesting aspect in this family interview related to Shona's reaction to her brother's illness. While she was deeply affected by Hamish's critical illness, she also used the situation to learn. At different points in the interview she drew comparisons between her studies and what she was confronted with at Hamish's bedside. Shona recalled, for example, that:

Dr. Y showed us the CT scans. Which was really good because the other consultant had said he had () brain and we kind of knew that that was a really bad injury opposed to just haemorrhaging. [] And when we actually saw the CT scan, Dr Y said, you know: 'there are the contusions, in his right frontal lobe and his left temporal lobe' and he – (.3) we could see them, we could actually see what actual damage he'd done.

Later in the interview she explained that:

Ahm, I think it's quite interesting. But I've never seen anything like it before, so that was a bit sort of scary at first, sort of going in and having all the machines around him. So – but no, I think I coped better because I knew a bit more than they (*her parents*) did, because I could go and look it up in my books and, you know, find out a lot of information and I think that kind of helped me deal with it a little bit better. So – certainly when he had the chest infection, 'cause I did pneumonia for this part of my course and it helped me learn, you know, for my revision as well. Because I looked it up, looked up pneumonia and then just go: 'yeh!' You know, it's – 'cause Hamish had it and I was really interested in it and I was really interested to know what kind of pneumonia he had, what antibiotics they were using, so I could learn that as well at the same time. []

Her ability to separate her personal feelings from the medical situation is indicative of a professional detachment evident in health care professionals (e.g. Chambliss 1996, Chesla and Stannard 1997). In other words, she was in the process of developing her own 'routinization' (Chambliss 1996) and well on her way to becoming a health care professional. This reinforces the argument that Shona observed the communication rules between medical professionals which, in turn, is the explanation why the medical communications differed between this family and others.

It is of interest that over time several family members across families adopted the ICU language. It was not uncommon that families spoke of a 'trachy' (tracheotomy) or 'sats' (oxygen saturation) or nurses 'doing their obs' (observations) in retelling an episode of interest during interviews. Learning some of the language enabled family

members to follow everyday life in ICU; they socialised themselves into the world of intensive care (Heimer and Staffen 1998, Lam and Beaulieu 2004). Interestingly, this was also the case for those family members linked to a health care profession in this study. Shona (family 5) commented that she had ‘never seen an ICU patient’ before visiting Hamish, while Fiona (family 8) pointed out that ‘intensive care was not part of my nursing education’ and therefore she had no nursing experience in this area. ICU was a different world to those they had known and encountered before.

Nevertheless, these families had an advantage since health care knowledge was part of their families’ resources and hence non-health care family members had an additional trusted source to ask for advice and interpretations. Jeff (family 8) commented, for instance, that he was ‘learning quite a bit’ himself while listening to Fiona’s questions and explanations. Linda (family 5) panicked when Hamish was diagnosed with MRSA which she thought was a ‘flesh eating bug’. Once Shona explained to her the difference, Linda was able to calm down again. It was this immediate information resource within families that had a positive impact on stress levels relating to clinical uncertainty.

Unit rules

Cassell (2005) observed that rules in ICU are dissimilar to those in everyday life. With the admission to ICU, the family’s access to the ill family member is controlled by others in the health care system, most often nurses (e.g. Clarke 2000, Farrell et al. 2005). In contrast to other wards within hospitals, ICU is a closed environment, accessible only through some sort of entry system. In the case of the study unit, the bed spaces were separated through a double door and visitors needed to ring a bell for attention. There was a sign informing visitors to wait for a member of staff to answer their call and to ring again if they had had no response within five minutes. This then was the official unit rule or procedure for entering the unit.

Deviating from this unit rule had the potential to cause friction and frustration within the group of nurses and families. Susan (family 4) recalled one such incident. She had been allowed to ‘just walk in’ by a nurse prior to being challenged rather aggressively (Susan’s description) one day by another nurse. Susan recalled that on:

[] [t]he 5. day, I walked in and it was a nurse who I had never seen before, she had obviously never seen me (.3) and I noticed that Jon's curtains on the window (*refers to the window in the door*) – because he was in a room on his own – were pulled. I would never just walk in if that was the case because I know that there's somebody doing something. And it was the nurse looking after Kati (*another patient*) stood there, and I said: 'Is it okay to go in?' And she was really quite (.2) you now, she went: 'DID YOU ring the bell?' And I said: 'Sorry?' (.3) 'DID you ring the bell?' (*the nurse*) (.3) 'What bell?' 'There's notice outside blablaba.' I'm sorry Susanne, who the hell in that situation is going to stop and read notices that are up on the wall or on doors?

Susan however was not against rules. While on the one hand she draws attention to the extraordinary situation families of critically ill patients are in, hence explaining why notices might go, literally, unnoticed, she also argued that:

[] the only suggestion I would have regarding (.3) nursing staff and whatever it is (.5) if there are rules they all have to sing from the same hymn sheet.'

It is evident in this example that confusion arose in both systems, that of the family and that of nurses. Controlling and managing access to ICU is based on the need to protect patients in these units from outside intrusions and allow time for interventions. Curtains or blinds fulfil exactly this function. They provide privacy for patients and nurses while interventions take place. As one nurse in a neonatal ICU explained 'we aren't running a freak show' (Heimer and Staffen 1998:59) emphasising that nurses take the protection of their patients very seriously. In this context, an ICU nurse, not connected to the study unit, told me recently that 'ICU nurses are quite territorial'. The ICU is, as Heimer and Staffen put it, the nurses' 'turf.' In Susan's case, the reported aggressiveness of the nurse suggests, that Susan was perceived as an intruder on her 'turf'. I suggest that the ICU is a social space inhabited by patients and different groups of health care professionals in which families are consequently viewed as outsiders.

Access to the unit is regulated in particular by nurses in accordance with a number of rules as a result of organisational structures but also nurses' own belief systems: all of which are unfamiliar and unknown to visitors (e.g. Hickey and Lewandowski 1988, Lewandowski 1994, Krapohl 1995, Chesla and Stannard 1997, Plowright 1998, Clarke 2000, Latimer 2000). Family members, in this context, are outsiders and accordingly

are viewed as visitors (e.g. Maxton 1997, Allen 2000, Farrell et al. 2005), separate from but connected to patients. Visitors have to follow the unit's rules. In entering the ICU without permission, Susan, as an outsider, had clearly violated this rule. Viewing the patient as essentially separate but connected to a family is different than conceptualising a patient as being embedded in a family system. These differences in perception have implications for the way nurses care for patients and families (Hughes et al. 2005).

It is further evident from this excerpt that there are differences between nurses and how they interpret and enforce rules laid down by an organisation. The variability between health care professionals and thus contact with staff can have variant effects on family members; it either empowers or frustrates them (Heimer and Staffen 1998).

Against this backdrop of two different worlds within the ICU, with families inhabiting one and health care professionals another, and both focusing on different objectives in relation to the patient (Strauss et al. 1963), 'Nursing in public' emerged as an overarching theme of ICU nurses' experiences with families.

Nursing in public

'Nursing in public' emerged as the consequence of an open visiting policy challenging ICU nurses to work with families and therefore this term is most fitting for nurses experiences with families in today's ICUs.

Perception of families

The scope of nursing is partly determined by nurses' perception of families which differed across focus groups and was influenced by nurses' positions within the health care hierarchy. Nurses with managerial responsibilities viewed families differently than those nurses working predominately or exclusively at the bedside

Families as units of interventions

It quickly became evident that this ICU's nursing management subscribed to a family nursing view in its approach to nursing care. This was implied by a nursing philosophy which identified the family as an important care recipient. One of the senior nurses underlined this in a focus group discussion when she said that

'[t]hey (*families*) know that they are part of the care, I think, as well. We quite often say that to relatives that: 'we're here as much for you as we are for the patients.' (S3)

This point of view was reiterated by another nurse whose remit included managerial responsibility in a different focus group. When asked what nurses saw as their role with families she answered:

'I feel my role with families – well, we probably have two different roles; one: if you are looking after a patient yourself, to keep them up to date and to have their questions answered and to look after them, what's the word? Psychologically look after them. [] And I think we do a very good job of that because the medical staff are kind of in and out. [] And sometimes when they've had a chat with medical staff they often come back to you and say: 'can you just go over that again with me?' which is good. So, I think that is part of our role when you're looking after a patient.

As nurses in charge sometimes- (.2) part of our role with families is to support the nurses in the bed space dealing with families. And also sometimes there can be situations or problems or issues with families as regards, you know, for instance social worker things, so – stuff like that and you need to look into that and help them out and to get them referred to the proper people and that. Ahm, so (.2) it's sort of a two-fold thing, I think.' (F1)

It is worth noting that in both groups other participants agreed with the expressed views of their colleagues. In reference to the latter excerpt, this particular nurse is actually touching upon three different areas of what ICU nursing entails in her view. Firstly, there is the focus on supporting families at the bedside as is evident in explaining medical information and 'going over it again'. Secondly, the family is understood as a socially embedded unit that might have issues or problems that need referring to other services outwith health care. Specifically this point brings out the difference in conceptualising patients as embedded into family systems as part of a wider social network and therefore changes the scope of nursing interventions considerably as opposed to patients who are viewed as separate but connected to families. It is obvious from the above accounts that both nurses viewed the 'family with a critically ill patient' as their intervention unit. This difference in perception then constitutes the difference in care delivery (e.g. Gilliss et al. 1989, Robinson 1995a, Kean 2001b, Hughes et al. 2005). This view was predominant in focus groups of nurses whose work remits included managerial responsibilities: that is those higher up

the hierarchy. A number of authors (e.g. Hickey and Lewandowski 1988, Hupcey 1998, Benner et al. 1999, VanHorn and Tesh 2000, Williams 2005) argue that the support of families is a classic area of nursing. However, it is often less clear what is meant by ‘nurses are supporting families’. As is evident in the above excerpt support can range widely between ‘going over information’ to ‘involving other services’. It is probably not a coincidence that there is very little research into family nursing interventions (Bell 1995).

The third topic raised in the above excerpt relates to supporting younger nurses in the bedspace in dealing with families. In this context, the term ‘younger’ relates not to chronological age but nursing experience. The ‘looking out’ for younger colleagues was echoed in a number of focus groups, including those of experienced nurses working primarily but not exclusively at the bedside (e.g. some E grades).

The patient as focus of intervention

While the nursing management of the unit promoted the family as part of ICU nursing, a different view on families emerged in focus group discussions with nurses working predominantly or solely at the bedside.

One of my initial research questions related to nurses’ views on families within the ICU setting. It was for this reason that I opened focus group discussions by asking what nurses saw as their roles with families. I had asked the same question to the following focus group of D Grade nurses. Their initial answers reflected the unit’s philosophy that they were there for both patients and families. During this discussion the following comment was made.

D 2: I think people get quite frustrated as well with families. I admit that. (.3) In public. (*Uncomfortable laughs from some group members*).

SK: That’s alright. You are not the first.

D 2: I won’t be the first and I won’t be the last.

SK: But can you say a little bit more-

D 2: Well, I feel – I think a lot of relatives feel they should be there all day with them and when they’re away all they’re doing is worrying about what’s

happening in the hospital. So, they feel they should be there all the time. (.3) But I also feel that when they're there all the time it kind of puts you up – it takes up so much time explaining things to relatives that I feel that sometimes the patients are losing out on care (.3) a little bit.

Group agreement: Yeh, mhmm.

The uncomfortable laughter that followed the initial statement alerted me to the possibility that this nurse had just broken a taboo in admitting 'in public' that people get frustrated with families. One meaning of going public relates to 'coming out into the open' (Oxford Dictionary 1995) and so this nurse was indirectly challenging the unit's management's philosophy of defining the family as care recipient. The discussion that followed made it clear that group participants could sympathise with the nurse's view that families can cause problems for nurses. This was underlined when participants named examples (e.g. aggressive, rude or abusive visitors) or where care had been delayed because family members were there 'all the time' (e.g. turning patients, mouth care) and thus patients were 'losing out on care.'

One fundamental difference in ICU compared to other areas of health care is the pathophysiological instability of some patients. That this focus is necessary in order to ensure the patient's best chances of survival is uncontested and evident in the following example.

E1: I was looking after an Asian patient who was quite sick and () and she got blood on the sheets and she was on something like 100% oxygen. She was really very, very sick and this man kept on saying: 'when are you gonna change the sheet?' (.2) And, you know, I said to them: 'I know it doesn't look very nice but it's not a priority at the moment.' And it was like: 'when are you going to change the sheets?' And I said- I just felt awful about that and I said: 'look, if I change her sheets she will die. She's not well enough to roll on her side (*Recalled in a quiet voice*).'

Nurses working at the bedside felt that the focus of nursing is 'the patient at the end of the day'. While in both examples nurses focused on patients as care recipients and not families the underlying rationales differ. In the first case, the scope of nursing is firmly based on the patient as separate but connected to a family, while in the second case the instability of the patient determined the focus of the nurse in order to safeguard this patient's life. This is not to say that these nurses did not understand the anxieties and

uncertainties families experienced while one of their members was in ICU. I already presented some data in Chapter 6 which clearly underlines their supportive nursing interventions aimed at family members, for example in defining themselves as ‘the first port of call’ for families or their role in translating medical information in bringing ‘it down to not laymen’s terms but understanding terms’ and so on.

I suggest that one of the main differences between these two groups of nurses, with and without managerial responsibilities, is rooted in their respective spatial distance to patients and families. This, in turn, had an effect on the emotional labour required by nurses in working with families. Families being there ‘all the time’ simply had a different impact on bedside nurses compared to those not exclusively caring for patients. It was therefore not surprising that experiences relating to families in ICU revolved around the discussion of unrestricted visiting in focus groups consisting predominately or exclusively of nurses working at the bedside.

Open visiting

The study unit had an explicit ‘open visiting’ policy. A sign at the entrance of the unit simply stated ‘open visiting’ as information to all ICU visitors. Open visiting or unrestricted visiting refers to family members’ right to visit at any time of day, for any length of time, of any age and in any numbers. Nurses did not impose a restriction on how many family members could visit. The unit’s rule, however, was not to allow more than two visitors at a time per bedspace. The following excerpts illuminates that in the case of the study unit, the rationale for this rule was based on a lack of physical space within the unit and around bedspaces.

SK: So, you don’t restrict any-?

F1: Yeh.

F3: We say two relatives/

F1: /per bed because of the lack of space/

F3: /per bed. But with some larger families, especially from different cultures and they just sometimes manage to have ten round the bed all the time. It’s a constant battle for the nurse at the bed space, and I think that is very tiring

because you'd say, well you only allowed two, but they just manage to sneak another couple in and another couple in and that's-

[]

F2: I mean it can get, it can get a wee bit full at times.

F3: It's when you've got to walk twice the distance round the bed 'cause you can't get in to the bed./

F2: /But/

F3: /And it's okay for an hour, but on an eleven hour or twelve hour shift you're just about in tears because you can't- you can't do it! (*Said in a forceful tone of voice*) You know.

This particular restriction on visitor numbers at the actual bedspace is common amongst ICUs and consequently often criticised in the literature as an example of nurses' power over visitors (e.g. Biley et al. 1993, Lewandowski 1994, Krapohl 1995, Plowright 1996, Carlson et al. 1998, Livesay et al. 2005, Farrell et al. 2005). The implication of this critique is the potential misuse of power by nurses in keeping family members out of the unit for their own gain (e.g. Chesla and Stannard 1997, Hupcey 1999). While this aspect cannot be dismissed, it is equally the case that ICUs often genuinely lack physical space close to patients.

Many family members remarked on the impressive array of technology gathered around many intensive care patients. There is, for example, the ventilator on one side of the bed, while various monitors might be on the other side. Add to this a number of intravenous pumps on stands in addition to those located at the bedspace and maybe dialysis equipment at one end of a bedside and the nurse's access to the patient is seriously challenged. There are times in ICU nursing where there is little physical space to accommodate visitors in addition to those who need access to patients. Yet, even under these circumstances, nurses will work, literally, around family members to support their need of being near the patient. It is for this reason that understanding restrictions on visitor numbers solely as the nurse's power over visitors is missing the point somewhat. Nurses frequently do not have control over architectural or structural layouts but live with them. Studies investigating visiting policies overlook this aspect of ICU nursing on a regular basis. Nurses' efforts in supporting families as visitors

despite space restrictions are simply the other part of the picture which too often goes unnoticed.

The problems associated with an open visiting policy surfaced early on during nurses' focus group discussions. In the following I will quote from one focus group discussion at some length since the points raised are identical to discussions in other focus groups. This way, the flow of the discussion and the interaction amongst colleagues is preserved. Prior to the following excerpt the nurses had discussed the emotional impact of families on them. While I return to this issue later in the chapter, my focus here remains on the discussion around unrestricted visiting.

E 4: The same is the case for reducing visiting hours because it is 12 and a half hours we have to put up with them and I don't think we should have to.

E 1: (In other ICUs) you're not allowed to visit until after ward rounds, so 12 noon. Other places you're only allowed visiting 2 – 8 or something.

E 4: Yeh.

E 1: I mean, I definitely think families shouldn't be in during handover, and I know we send them out during handover.

E 3: Yeh. Unless they've been here a long, long time. (*Group agreement*)

E 1: Even then, because sometimes you pass on some very confidential stuff that you don't really want them to hear. Not that it's something awful about them but, you know, they can pick up some things wrong.

E 2: Somebody was saying about one patient where her husband just walked in and he said: 'why shouldn't I, I'm sitting outside all day.' But it was something like – his wife was on the bedpan or something and it's just not appropriate for them to come in. [] But they (*families*) have to sometimes sit outside for half an hour.

E 5: I think families get angry if they don't-/

E 2: /Yeh.

E 5: We generally say; 'don't come before 12.00 or 1.00' And if they come at 10.00 in the morning they get angry because they've had to wait for an hour and a half outside while we wash the patients or/

E 1: /do the ward round. (*Group agreement*)

E 5: They can't be in during the ward round because of confidentiality for every patient, not just their patient, and they don't understand that, but we tell them specifically: 'don't come in until after 12.00'.

SK: And why do you think they come in at 10.00 then?

E 5: No idea. (*Laughs, group agreement*)

These issues were raised in almost all focus groups in one way or another. A number of points can be drawn from the above excerpt which relate to firstly, control over working time and patient care, including confidentiality issues; secondly, adherence to unit rules and, thirdly, nurses emotional management of working with families in ICU.

Control over working time

During focus group discussions nurses argued that a constant flow of visitors inhibits patient care. With families being 'there all the time' (D1) some nurses felt the need to delay certain care activities (see above). In theory, the unit's philosophy of defining families as care recipients and consequently integrating families into care should not have had any delaying effect on nursing care. Yet, families were often seen as a distraction from their real work and focus, namely that of looking after critically ill patients. The perceived interference in care was two-fold: firstly, the presence of families required nurses to attend to the needs of families (e.g. information needs, explaining procedures, integration into nursing activities) and secondly, care activities were delayed due to the presence of family members to either allow families to be with the patient or to protect the patient's right to privacy while care is being carried out. This specific argument with its two dimensions is not unique to nurses in this study but is one that has been brought forward by ICU nurses elsewhere (e.g. Dunkel and Eisendrath 1983, Biley et al. 1993, Chesla 1996, Chesla and Stannard 1997, Maxton 1997, Plowright 1998). Interestingly, the view of families as hindrance to care runs counter to nurses' beliefs that 'families are important for patients' (S1, E4) as a source of support in their recovery process. Again, this point of view was common to ICU nurses in this study and can also be found in research literature (e.g. Simpson 1991, Hupcey 1999, 2000, Bergbom and Askwall 2000).

On the basis of the views expressed by nurses in focus groups it appeared that the issue was not the policy of open visiting as such but the consequences of this policy in relation to nurses' control over working conditions. It became apparent across focus group discussions that nurses, faced with open visiting policies, were actively looking for strategies to remain in control of their working environment. Sending families to the waiting area, outside the unit, was one such strategy that nurses employed to ensure privacy and confidentiality for their patients. It is not a coincidence that nurses understood themselves as the patient's advocate and as such protected patients from others, including family members if necessary. This point is reinforced by the example given in the above excerpt where the husband ignored the unit's rule of being called in and walked in on his wife on the bedpan. Equally, Susan's earlier example of being challenged by a nurse for ignoring the same rule also falls under the 'patient's privacy headline'. A further aspect of nurses' view on protecting patients' privacy is evident in the following excerpt. Here, nurses discussed the inclusion of family members in the care of their critically ill loved one.

D&E 3: Yes, I think they should have a choice. The thing is that certain relatives- I certainly wouldn't want - you know, if I was in a bed and my husband would help cleaning me up, you know, I wouldn't want that. So, I think that's- you know that's my position. Because they're not awake to consent or whatever.

D&E 2: It depends how the person feels, of course, and/

D&E 1: /Yeah and dignity of the person is important. I just think- and I think a lot of relatives don't want to participate in some aspects of the care.

[]

D&E 2: The other side of the coin is you've got someone very sick and unstable and the bed bath- (and then) something happens. And I've seen where someone in that bed space has been silly- because you have to be in a controlled environment and somebody who is not even used to a hospital never mind they come in and they see this (*overriding speech*). I just think it's a time where a patient's dignity must be respected. I know that the sort of Hindus and things have a different culture, that's fine by me, () bed bath, as long as they don't pull lines out. But I just think it's a special thing and it's customary in this country, your body is your temple and it should be kept that way. And I respect that.

In ICU, as one of the above nurses is pointing out, the majority of ICU patients are 'not awake to consent' (D&E 3) and are therefore not in a position to agree or disagree with a visitor being there or a family member participating in care. Nurses were passionate about protecting their patients' privacy and felt strongly that the time of ward rounds or interventions are just 'not appropriate for them to come in' (E5).

In particular nurses' view that family members should not be present during ward rounds raises the issue of functional uncertainty and the withholding of information 'because sometimes you pass on some very confidential stuff that you don't really want them to hear' (E1). This 'confidential stuff' could relate to medical information that needed a lot more than just mentioning but explaining, including translating medical language, to families. If families overheard this confidential information during ward rounds the nurses' workload might be increased, the patient in the neighbouring bedspace's rights to privacy and confidentiality might be compromised, or there could be issues of confidentiality within the family. I am, for example, aware that there was a family during my sampling time where the patient had contracted a disease from his wife. While his wife informed the health care staff of this circumstance, she also requested that this information was not to be passed on to their adult children. Nurses do find themselves sometimes tied up in a family dynamic which they do not have control over but which has implications for how they work with families. Protecting the confidentiality of patients and sometimes family members is a crucial and undeniable part of nursing.

However, the patient's right to privacy frequently serves nurses as a justification to send families outside while interventions take place. While this is an argument which can and should not be dismissed lightly, it also has to be recognised that nurses themselves gain from the patient's right to privacy. Having the power to send visitors outside creates a breathing space for nurses to work without being constantly observed by outsiders. The perceived interference of families on nurses' control over their working time became evident in a number of contributions. These nurses spoke about families that can be 'a bit of a distraction or diverting you to certain tasks that you wouldn't do, like giving mouth care and things' (D5) at that particular point of time or recalled families which 'just sit there, just for hours and hours and hours and we can't

get in when you're trying to do something. They just sit in the way for hours' (D&E3). A number of nurses reacted by sending families outside arguing along the lines of the following contribution.

D4: I think, you know, like with us having open visiting times and I know a lot of people are against that. But I think by having that that you can say: 'I'm sorry, do you mind if you leave now?' So that- you have almost got more control because you can say: 'right, now is patient time, I'm sorry, you will have to go out now and then you can come back in when it's finished.' Whereas I would feel awful if they had two hours in the morning and two hours in the afternoon, I would be thinking: 'oh gosh I've got ahm (*Overriding group comments*) () for two hours. Whereas because it's open I can say: 'well, no actually we need-' the patient then takes priority, we need to do this, you know.

The view that nurses are there 'first and foremost' (D&E1) for the patient was reiterated by most nurses during discussions. This then served as argument to send family members outside in order to protect their patients' privacy whilst carrying out interventions and at the same time ensured nurses some space for caring. Considering the views expressed by nurses, it appears that nurses' need for privacy in caring for critically ill patients is at the heart of the argument against open visiting policies. It is however an unrecognised need that runs counter to calls from nursing scholars and health care policy makers that promote a patient centred service and thus, directly or indirectly, the integration of families into care (e.g. Lynn-McHale and Smith 1991, Department of Health 1997, Audit Commission 1999b, Benner et al. 1999, Williams 2005, SEHD 2006a, 2006b). It is at this point that the parallels between children's nurses working in partnership with parents and ICU nurses supporting families become obvious. In integrating parents or families into nursing care, nurses are required to give up some of their institutional power over family members and, as a consequence, some of their control over their working environment.

'Nursing in public' is similar to the work of Philip Darbyshire (1993a, 1994), whose phenomenological study drew out parents' experiences of living-in with sick children during their hospital stay. He used the term 'parenting in public' to capture parents' parenting experiences under the watchful eyes of children's nurses. Although the roles are reversed in that nurses are the observed rather than the observer, Darbyshire identified similar problems to those evident in this study relating to structural

organisational issues but also to the intrusion on privacy for one of the groups concerned. In effect, there are striking parallels between children's nurses required to work in partnership with parents and ICU nurses supporting families. The partnership in care approach, which provides parents with a space to care for their hospitalised child, was a change in paediatric nursing practice following the Platt Report in 1959 (Darbyshire 1993b, 1994, Coyne 1995, Casey 1993, 1995, Lee 2007). In paediatric care, parents became co-clients as a result of these changes, representing a hidden area of nursing work due to their own needs for care by nurses (Callery 1997b). Williams (2005: 7) makes a similar argument for ICU nursing in stating that 'it must be recognised that families are also recipients of care in ICU and have needs that should be met [].' It is this aspect of working with families that poses similar challenges in ICU nursing as it did and still does in paediatric nursing (e.g. Whitehead 2005). In examining the 'partnership in care' philosophy in a grounded theory study Coyne and Cowley (2007) found that participants (children, parents and nurses) reported a considerable disruption to their social world and their attempts of 'finding a balance'.

Aspects of the challenge mentioned above are evident in the subsequent tension that emerged between the needs of families and those of nurses. Time and again families in this study reiterated their need to be near their loved one. This is a need that has been recognised and documented in earlier needs studies (e.g. Molter 1979, Leske 1986, Norris and Grove 1986, Coulter 1989, Hickey 1990). This particular need was one of the reasons why families turned up at times which were inconvenient from an ICU organisational perspective (e.g. ward rounds, bed bath time and so on). Family members however also understood and commented on 'being sent out' as something nurse specific as the following excerpt shows.

Jeff (family 8): But there is another side to it as well. We didn't want to interfere with any medical assistance he's (*Kieran*) getting by being there. Because I feel we are in and out a lot in here (*waiting room*). Sometimes it depends which nurse is on as well, sometimes we can stay in when they're doing certain things, and some of the nurses don't like us to stay. So we come out.

It is evident in Jeff's comment that he recognised the impact family members had on staff and that 'it depends which nurse is on' whether they can stay or have to leave the

unit for interventions. That the decision of sending family members out is often a subjective one is reiterated by other studies (e.g. Hupcey 1998, 1999). Families had a vested interest in the best care for their members and argued that they ‘didn’t want to be in the way’, ‘interfere with any medical assistance’ or ‘pulled myself together’ so that nurses could focus on the patient. Another example is Susan (family 4), who recalled an episode where she left the unit and drove home one night because she observed the nurse’s distress with her being there. Plowright (1998) points out that nurses in her study asked family members to leave because they thought family members were observing them and felt uncomfortable about this. It is true that family members, or visitors in more general terms, observe nurses. As I outlined in Chapter 6 and at the beginning of this chapter, nurses’ behaviour is a source of information, providing some clues that help families in assessing and understanding the situation. Though observation was never mentioned as a reason to send families outside, nurses in this study were well aware that they were being observed by visitors. As one nurse puts it:

‘I mean what other job- you know you don’t go and watch them in the tax office 24 hours a day and watch the taxes being done. I mean what other job can you come in and watch somebody in the work that they do in their day to day life.’
(D&E 3)

Nurses in other focus groups reiterated this statement in arguing that ‘we work sort of totally under observation all the time’ and pointed out that ‘it would be nice not to be observed all the time’. It has to be said that this aspect of ‘nursing in public’ did create stress for some nurses; either because the patient was so unstable or demanded their undivided attention or because a nurse was new to the environment and had yet to develop ‘multitasking’. And some nurses just did not like being observed.

What is also evident in Jeff’s comment is that the difference between nurses in their approach to families made it difficult for families to know what was expected of them. Families had to determine a nurse’s preference by trial and error as to whether they would be tolerated at the bedside or made to wait outside. Naturally, variability always has the potential for conflict and some families reported challenging nurses if they were send outside for care activities they had witnessed or helped with before.

I pointed out earlier that participating families' need to be near their loved one is in line with over two decades of needs research. The flexibility that a policy of open visiting provides is crucial for families in meeting their family obligations (e.g. picking children up from school) and fulfilling their need 'to be near' at a time of uncertainty. This view is also expressed by others (Sims and Miracle 2006). Some nurses acknowledged this in arguing that 'it must be reassuring for families' to have flexibility in visiting hours. At the same time one has to recognise that this change in policy has a profound impact on nurses and their working conditions. Rosenthal and colleagues' comment sums this up nicely:

[t]he open visiting policy leads to a situation where the presence of family members cannot be confined to a narrow and predictable time segment. [] [T]his creates strain for nurses in several ways. The nurse may no longer be guaranteed privacy in carrying out nursing tasks on and around the patient; these may have to be done in the relative's presence, or the nurse must request that the relative leave the room, thus risking conflict (Rosenthal et al. 1980:99).

The conclusion that the introduction of an open visiting policy is beneficial for families but has both advantages and disadvantages for nurses is obvious. The loss of privacy for nurses on their 'turf' and the unpredictability of when and how many visitors will arrive considerably influenced nurses' working conditions. Surprisingly, this aspect of open visiting policies is rarely addressed within this area of nursing research. The unit's policy of open visiting and the resentment of some nurses towards families surfaced with the issue of open visiting earlier on in focus group discussions. Another factor closely linked to open visiting is the observance of unit rules.

Adherence to unit rules

Rules, as has been pointed out at the beginning of this chapter, differ in ICUs compared to other hospital wards or everyday life. Families, as outsiders, face the difficulty of entering a highly specialised ICU world in an attempt to access and support their ill family member under conditions and rules unfamiliar to them (e.g. Darbyshire 1994, Anspach 1997, Heimer and Staffen 1998). Nurses, in contrast, were faced with protecting their 'turf' in an effort to create enough private time to nurse their critically ill patients (e.g. Chesla and Stannard 1997, Allen 2000, Farrell et al.

2005). Nurses are embedded in a complex health care system governed by rules, routines and structures serving the preservation of the system. One aspect of this system is a complex, hierarchically ordered, division of labour. The time of ward rounds, for example, reflects the structure of physicians' working days. The same holds true for other services like physiotherapy, laboratory and radiology and so on. James observed cogently that 'negotiating day-to-day care is both a matter of organisations and organising' (James 1992:494).

Earlier in this chapter I referred to Susan's (family 4) experience of the variability between nurses in demanding compliance to unit rules and Susan's request for consistency. While this request is understandable, following rules rigidly would compromise individualised care. Individualised care, in turn, is a mark of professional care, an expression of 'caring for' a patient as an individual. Nurses across focus groups reported examples where they had deviated from unit rules in an attempt to individualise care. The rule of not having more than two visitors per bedside can serve as an example.

F 1: I think we are good at looking at specific needs like, say there was a certain thing, 6 months ago, where somebody wanted prayers or something being read but it involved all of the family being there. (.2) That is not a problem at all, you know, come in for half an hour and do all of that. And I think, you know, if somebody says to you: 'oh, we'd really like to do this' or 'I wonder if that is possible' then we would facilitate all that kind of stuff. Or 'my sister has not been in and I'd quite like to come in with her but I don't like being here without my mum', well then, that's fine maybe for 20 minutes or whatever. All three of you come in while one supports the other sort of thing. I think we are good at that kind of thing.

F 3: Yeh. I think a lot of the time. We're quite easy about, you know – unless we're really busy and then, you know, usually we say two, but we are quite easy and –

F 1: I think it's – just about the problem when there's loads of relatives and it's such a confined space out here for them to sit in and they're chatting to each other and they find out that: 'Have you had three at your bed?' 'No, we've only been allowed two.' And this is what happened before (*laughs*) and it sort of spreads like wildfire and then they come and ask you why they had three and I've only had two, and this kind of thing. So, I think, you have to be a bit consistent, except for special things, you know.

It is 'not a problem at all' to accommodate special requests from families which support their need to do something special for their critically ill family member or help another family member visiting for the first time. Nurses were 'quite easy' and forthcoming about this kind of support. What is of interest here is the time limitation indicating that nurses remained in control over their working conditions. It appears that as long as the exception was a result of negotiations between parties, nurses were quite happy to accommodate families' wishes. This is one of the situations where power differences between nurses and families became evident. Naturally, as a representative of the health care system, nurses had more power than families within the system. Yet, cooperating with families was an expected and practiced part of ICU nursing by nurses.

Making exceptions was however not without consequences for nurses. It is evident in the above excerpt that separate families talk to each other in the waiting area and 'compared notes.' Perhaps not surprisingly, other families challenged the imposed rule of 'not more than two' as a consequence. It was however those families or family members who ignored rules which created conflict and strain not only between families and nurses but also between nurses. Susan's experience at the beginning of this chapter can serve as one example where nurses differed in their views regarding Susan's access to the unit. A further example relates to South Asian families. In a climate of political correctness, nurses cautiously raised issues surrounding extended South Asian families. The concept of family differs significantly between Western and Asian societies. Within the cultural context of South Asian families, families tend to be larger and include extended family members (e.g. Schuman 1999, National Statistics 2006, Georgas 2006). Nurses discussed the tension between 'culturally sensitive care' and the physical lack of space to accommodate large South Asian families both within the unit and also the waiting area. The lack of control to organise such visitor flows resulted in stress and strain for a number of nurses.

D 1: I find that a wee bit, sort of Asian families (.3) tend to just walk in because it's obviously their culture. []

D 5: And say two to a bed. (*Group agreement*)

D3: They have massive families, I mean, they just keep coming. You just can't believe it.

D 1: Yeah. You can't – it's sort of, you can't minimise who can come in because they're all extended family, so they all have to come in and you sort of-

D 3: Doing a relay from about 6 p.m. when everyone has finished work until about 8 p.m. and ah, every person that comes in, it's not like they go back out and chat to each other about what you've explained, you just do the same conversation – how are they today. And you've done this about three times so far in an hour and it's just like: 'well, you know, they are quite stable.' And like they haven't gone out and discussed it themselves. It's like only the nurse can tell me how he is today, we can't talk about it between ourselves.

It is of interest to note that nurses across focus groups raised the issue of extended South Asian families and the problems this presented for nurses very cautiously. One nurse, in a different focus group, asserted that she was not making a 'racial comment but merely an observation.' The resentment nurses felt for families who ignored the rules referred to the fact that they ignored the rules, irrespective of their ethnic background. Families who 'just walked in' did not go unnoticed by other families waiting outside. Naturally, nurses were challenged at times to explain to other families 'why them and not us.' This in turn increased the emotional strain for nurses since conflict with families ignoring the rules as well as families following the rules was a real possibility. A further topic the above excerpt touches on is the additional work families can create for nurses in relation to information giving (e.g. Medland and Estwing-Ferrans 1998, Pecchioni et al. 2006). This, however, is independent of ethnicity or family size but relates to dynamics and communication patterns in families.

It is apparent that organisational rules and exceptions to these rules created potential for conflict with other families since they 'are chatting to each other.' In the context of paediatric nursing, Darbyshire (1994) points to exactly the same tension when nurses were trying to reconcile the wishes of an individual parent with the universal concern of the ward. With regards to hospice care, James (1992) observed a similar phenomenon, namely that the failure to follow routines results in a disruption to the social order of an organisation. Ironically, individualised care has to fit into the organisational structure of a unit. In this sense, the term 'individualised care' is

misleading since predefined organisational structures (e.g. eating times, bed bath times, medication and so on) lack the necessary flexibility to truly individualise care.

It was obvious that nurses agreed to exceptions in an attempt to individualise care. Nevertheless, these exceptions needed to fit within the universal concern of the unit and thus health care as an organisation. At the same time the variability between nurses in following and enforcing rules was highly subjective and nurse dependent, and hence confusing for some families. The strategy of 'being consistent' and sticking to unit rules was believed by some nurses to be a means to protect them from conflict situations. However, it was not necessarily 'sticking to unit rules' but the nurses' management of interactions, and so their emotional labour, with families and other health care professionals which was at the centre of their own protection. I tend to agree with Fineman (2001) when he argues that it is the skilled 'emotion work' that lies at the heart of organisational control.

Emotional management

The degree to which nurses were able to communicate with families influenced the smooth running of the unit and nurses' well-being. In this context, emotion work is an important factor in regulating social relationships (Fineman 2000). The following example is a case in point.

D&E 3: There's one family at the moment that we had a problem with in the last kind of fortnight when basically they were specifically coming in for the nursing handover, which was- (.3) the problem was that that was becoming very intimidating to a lot of the nursing staff. And it was getting to the point where a lot of the nurses didn't want to go in and look after this patient. Because it's quite intimidating to- you know, you feel like a performing seal at that time and have to tell those patients your whole life story or whatever in front of this () audience. And we ended up having to speak to this family and kind of take the tack that, you know, have you had a bad experience? Do you not trust us? Is this why you want to be here? You know, and they just generally kind of put it back on us and said, it was actually because they wanted to feel that they kind of completed the day and handed him (*the patient*) over themselves to the next sort of shift of care, do you know what I mean? That's how it was and that's how they said that they coped. (*overriding*) They were a medical family./

D&E 1: /So they just felt that by hearing it from us that- they didn't actually speak to medical staff an awful lot either, they just put all their communications through us. And they were coming in, hearing the handover and were happy

that- basically 'I'm happy with the care he's had.' There was no problems with the care that he'd had or that they had, there wasn't any problems. But it was a reassurance thing for them./

This discussion revealed a number of interesting points. Firstly, nurses realised that it was they who had the problem with the family, not vice versa. Significantly, the problem was rooted in a lack of communication between both parties. The family's need to be near their family member at a certain time of day had triggered a very different interpretation by nurses than was the intention. Nurses 'ended up' talking to this family only after many nurses felt uneasy about caring for this patient.

Secondly, the interaction that eventually took place was based on nurses' belief that this family must have 'a problem' with the care their member was receiving. The line of questioning nurses took when eventually talking to this family suggests that their presence during a shift handover was viewed by nurses as a control mechanism. This belief, in turn, created a situation where nurses felt uneasy about 'performing in front of this audience' since they could not be sure whether they actually met the family's expectations of care. Yet, as the conversation with the family revealed, their presence had nothing to do with the care their family member received but was about the family's need to be near their loved one at the end of the day, enacting a ritual that says 'have a good night – we'll see you tomorrow.'

Thirdly, it is apparent in the reactions of nurses that 'nursing in public' in conjunction with a lack of communication can lead to serious tensions and stress between nurses and families. In this context, Lazarus (1999) draws attention to the interdependence of stress and emotion. He argues that 'where there is stress there are emotions' and that this applies often, although not always, to the reverse situation, bearing in mind that stress is not always negative (Lazarus 1999:35). A similar argument is made for the interdependence of belief and emotions (Frijda and Mesquita 2000, Clark and Brissette 2000). In accepting these interdependencies it seems self-evident that the management of communication and emotion is paramount in order to regulate the social relationship between nurses and families; sometimes in an effort to control potential negative effects on caring.

It is not unusual that care of difficult patients or patients with difficult families is shared amongst nurses (Allen 2000). This is done at the beginning of a shift when patients are allocated. In these cases nurses rotate more frequently in order to share the apparent burden. For the patient, continuity in care is jeopardised and as one nurse poignantly remarked in being classified as a difficult patient or family ‘they shoot themselves in their own foot.’ It is necessary here to distinguish between families who actively complain and those, like the one in the example, who are perceived as being difficult. While in the first case there might be a real problem, in the latter case there is a perceived problem by nurses which might well turn out to be non-existent. The important point here is the avoidance of communication.

It appears that, had there been a proactive communication between nurses and family, the stress nurses experienced due to the family’s presence and their subsequent belief that the family must perceive their care as unsatisfactory could have been avoided. In fact, the whole situation can be interpreted the other way round since this family did not feel the need to talk to medical staff which suggests that they trusted nursing staff. What this example underlines is the emotional work and management that is inherent in nursing.

In past decades, as Mann (2005) points out, emotional labour has been ‘the focus of much debate and empirical enquiry’ and particularly so within nursing. The notion that nursing requires a great deal of emotional work has indeed been established for some time by a number of authors (e.g. Smith 1991, 1992, James 1992, Aldridge 1994, McQueen 1997, Bolton 2000a, 2001, 2005, Bone 2002, Lewis 2005).

That nursing work goes beyond the physiological focus and challenges nurse on many emotional levels is evident in the following excerpts.

S1: Yeh, having said that the nurse is best placed to communicate with relatives, I would say that the person best placed is the nurse who knows most about the patient and has the confidence to deal with relatives and who has excellent interpersonal skills. So, there is a lot of new staff coming into ICU where dealing with the relatives is one of the most stressful parts of the job. And I think that’s perhaps because they (*nurses*) feel a bit insecure in their environment, until they feel confident in their environment they also find that quite stressful. Ahm, particularly if the relative, as is almost usually the case is

anxious, perhaps coming across as a bit hostile, you know. I know myself having been a relative you kind of come in wanting to know everything and being particularly picky about your loved one's care. And if it's a child I can imagine even more as a mother or as a father where you're used to doing everything for that child, being around that child, that you would feel terribly helpless. And you would be watching strangers look after your child and you would want to know that that child was safe in their hands.

SK: So what do you do then to establish the relationship between the staff and the family?

S2: It goes back to basics to begin with when families come in, you introduce yourself, ahm say who you are and basically be pleasant, offer them a seat and give them an update on progress. Ahm/

S3: They know that they (*the family*) are part of the care I think as well. We quite often say that to relatives that: 'we're here as much for you as we are for the patients', so they don't feel that they're a hindrance asking questions. Because I think sometimes maybe in that situation with that gentleman this week, sometimes they feel that they can't offload until it gets to a crisis point and then they just get the whole lot coming out. So, making them aware that they're allowed to ask questions and use the nurse to reduce their anxiety.

In another focus group nurses discussed how they support young people and their parents during a time of critical illness:

D4: I think if you support the parent so that they are feeling reasonably comfortable they will then be able to comfort the child. So, although we are going to be comforting the child and the parent as well, but you know like the initial things, making sure that the parent is happy and reasonably comfortable (.2) and so they then introduce the child.

D3: I don't think anything should be hidden from children. I've got children myself and just think, just be open with children and you shouldn't hide and say: 'oh daddy's gone away'/

D1: /Yeh/

D3: /and he (will) come back/

D1: /So, if he dies and things like that, how do you explain that to them (*Group: yehs*)

D4: You just don't realise what- that is such a big time in their life and it's going to have such a huge knock on effect when they start having their teenage problems or whatever because then you've built up a lie, you told them a lie about him. (.2) And I actually tell- (*overriding*)

D2: When families ask me for advice on should they bring the children in I say: 'I don't know.' (.2) Some people believe you should and some people believe you shouldn't. And then I just say: 'When my mum was in hospital for a big part of my life and I was quite'- well, I was nine. Well, I would say that was quite young and 'I wasn't allowed to see her and I was told that she would come home and blah-blah-blah' (*sing-song voice*) and she was in hospital for weeks and weeks and weeks and eventually she did come home. (.2) But the whole time I thought: 'my mum went away, she doesn't love me.' And even when I was older- it took me a long time through my teenage years and actually I held it against my mum because I hadn't understood how ill she was (.3) and it just didn't sink in. And I explain that to the relatives and say: (.2) 'I just wish I'd know, I thought my mum didn't love me.'

SK: How do they react to that?

D2: They usually bring the children in (*group laughter*). I feel guilty that it was because of what I've said (.2) but that's my only experience (). And I do believe that children cope with things really quite well. (*Group: Mhmm*)

These data seem to suggest that the nurse-family relationship can be 'the most stressful parts of the job' (S1), in particular for more inexperienced ICU nurses. Less experienced nurses did comment on 'being overwhelmed by relatives' (D 3) or where perceived as feeling 'quite intimidated at times by the way the family can ask questions' (E2) or where nurses in charge 'got to suss out if the nurse at the bedspace needs help with that' (*talking to relatives*) (F 3). At the same time, as is evident in the second excerpt, nurses were asked for advice which was not directly related to the patient's critical illness situation itself but addressed a family issue – here the visitation of young people.

These are the aspects of nursing work that relate to, what Strauss and colleagues define as the 'ingredient in any kind of work where the object being worked on is alive, sentient, reacting - an ingredient either because deemed necessary to get the work done effectively or because of humanistic considerations' (Strauss et al. 1982:254). Strauss and colleagues (1982, 1985/1997) were amongst the first writers to raise the issue of emotional work in hospitals. They went on to argue that the notion of sentimental work was 'nothing new' but merely recognition 'that there was more to medical/nursing work than its physiological core.'

Interestingly, it was not the term ‘sentimental work’ but ‘emotional labour’ that found its way into nursing literature and research. Emotional labour, as term and concept, was introduced by the sociologist Ariel Hochschild. In fact, Hochschild’s work has been so influential in this area that there is little that does not draw on her concept of emotional labour (Fineman 2000, Bolton 2005).

In her seminal work, Hochschild (1983) investigated the emotional work of debt collectors and flight attendants. She defines emotional labour as something that requires

[] one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others – in this case, the sense of being cared for in a convivial and safe place. (Hochschild 1983, p 7)

And goes to explain that emotional labour is

[] the management of feeling to create a publicly observable facial and bodily display; emotional labour is sold for a wage and therefore has *exchange value*. (page 7, footnote, Italic in original).

Like Strauss and colleagues, Hochschild draws attention to the fact that work has physical as well as emotional aspects. Unlike Strauss and colleagues, Hochschild emphasised the monetary value of emotion work in organisations. It is this link between emotion work and commercial gains that is a key concern in Hochschild’s (1983) work. She argues that private and public feelings become enmeshed for the commercial gain of a company, which in turn, can result in emotional confusion for the employee in that his or her feelings become *transmuted* (Hochschild 1983:19). Emotion work, in this context, involves surface or deep acting. Surface acting is understood as the management of one’s expressions rather than feeling. Thus, a facial expression is not necessarily revealing how one feels; it is ‘put on’, it is not ‘part of me’ (Hochschild 1983:36). Deep acting, in contrast, is an actor’s work on feelings that result in actually experiencing or feeling the emotion conveyed (Mann 2005:305). It becomes part of oneself.

In the following analysis I draw however on Bolton's four-fold scheme of emotion management: 'pecuniary' (emotion management for commercial gain), 'prescriptive' (emotion management according to organisational/ professional rules of conduct), 'presentational' (emotion management according to general social 'rules') and 'philanthropic' (emotion management given as a 'gift') (Bolton 2000b:156).

Prescriptive and pecuniary emotion management

In a clinical situation nurses are required to 'read' the changing emotions of family members (Lewis 2005). Acting and reacting in a professional manner is paramount for maintaining a social relationship between nurses and families. In the following excerpt, nurses discussed the emotional labour involved when meeting family members on their way home.

E 1: And in some ways that's quite difficult, you know when – (.3) you can accept it during your shift and when you're here and you're getting paid to be here. That's fair enough. But if, you say, are leaving the hospital and they (*visitors*) start coming in/

E 2: /they're coming in/

E 1: /yeh, and you feel sort of, feel- (.2) you know, most times you feel: 'o.k., I'll speak to you for a few minutes' but sometimes you just feel 'this is my time. Get lost. Go and ask the nurses on there.' You know, 'I've been nice to you for 12 hours and I can only be nice to you for so long.'

E 2: They want a report in the car park.

E 3: The smile has gone. (*Group agreement.*)

E 1: It's important to protect your time. I know that people say 'it's a caring profession' but some – You know, we're all human and 12 hours is a long time to sort of be tolerant and be kind to these people (*families*).

(This is the preceding discussion I referred to earlier.)

It is evident from these contributions that meeting family members outside the social space of an ICU can create additional strain and stress for nurses. Nursing is a 'caring profession' and it is this prescriptive aspect of emotion work that requires nurses, even after a twelve hour shift, to act as nurses in following implicit feeling rules of their profession. It became apparent over time and across focus groups that 'being nice'

was part of the professional role of nurses and hence constitutes work. The nurses' gain for acting in accordance with these implicit feeling rules was a social relationship with families which enabled them to 'get the work done effectively' (Strauss et al. 1982). This was achieved through maintaining a (caring) face, a term Goffman (1967/1982) used and Bolton (e.g. Bolton 2000a, 2000b, Bolton and Boyd 2003, Bolton 2005) draws upon in her typology, in that nurses implicitly accepted the responsibility for the interaction in progress. It was their behaviour, their following the 'traffic rules' of interaction (Goffman 1967/1982) that was of importance to the unfolding event. Consequently, I was interested in how nurses actually deal with a situation like the above.

E 1: Well, I try – you try and be as diplomatic as possible. [] I've worked hard for 12 hours today and I've given the care to the best of my ability and, you know, I'm off. And half of me thinks 'yes, do try and be kind to them' but the other half of you sort of thinks 'well, this is my time.'

The nurse is clearly torn between what is expected of her as a professional by the family and implicitly by the health care service and her own needs. Yet, even if off-duty, this nurse attended to the family's information need. Clearly, her prior existing social relationship with the family and the expectation of the family is of significance. Had she not responded in a favourable or acceptable way to the family, she would have risked 'losing face' (Goffman 1967/1982), which in turn could have had implications on her on-going relationship with the family for the duration of the patient's ICU time. Nurses understood this. The nurse's view that nurses would try and 'be diplomatic' and speak to family members 'just for a few minutes' before heading off is indicative of a prescriptive emotion management that complies with the expected professional behaviour of nurses by society and nursing colleagues.

What is of interest is the insight that ICU nurses displayed a face which fitted the situation and which was deemed socially appropriate and expected of them. They are, as Bolton (2001) put it, 'emotional jugglers'. This is an important point since it is exactly this kind of emotion work that 'keeps the organization organized' (Fineman 2000).

The following excerpts, taken from different focus groups, are further examples of nurses' emotion management.

E1: I can remember this relative quoting the Patient's Charter at me once. 'It's my right to this!' and I said: 'fair enough but at the end of the day it's my job to look after your wife and you know. And you're not helping.' I said to him: 'Yes, I am quite happy for you to come in but I'm not happy for you to come in now while I do ()' I said: 'so, you will have to wait.'

Or

D&E 2: I think, the difficult experience that I've seen over the years, is families' grief at the time and their logic and their sense of behaviour goes out the door sometimes. And they're very aggressive, purely presumably because of the state they're in and they've no other way to control it. That happens a lot. They get verbally aggressive and there's a complaint syndrome occurs after that for a while. And it's really down to the fact that they're so uptight, so distraught that they're just looking out for something or someone to hit, metaphorically speaking. So, that's a difficult part, I think. []

And

S2: I had quite a difficult experience yesterday with a lady's husband who wanted to make a complaint. Essentially a number of reasons which, I think, boiled down to lack of communication on our part and his perception has been a little bit (.2) over-optimistic I think. Ahm, so I had to try and resolve that issue yesterday which took over an hour.

In all given examples the form of prescriptive as well as pecuniary emotion management of nurses is evident. While they were at times shouted at or accused of something, nurses remained calm and tried to either excuse an individual's behaviour because of 'the state they're in' or tried to explain and provide further information to a family member in an attempt to improve their understanding of a critical health situation or to guard a patient's privacy during a care activity.

The above examples also draw attention to the blurring of boundaries between different types of emotion management. Specifically, the 'new public sector management philosophy' in which patients are re-conceptualised as customers and nurses are consequently asked to present themselves with a smiling 'calm and caring face' to ever demanding customers, patients and family members alike (Bolton 2002, 2004, Bone 2002), underlines the need for a pecuniary emotion management by

nurses. Visitors who 'quoted the Patient's Charter' at nurses accentuated tensions between pecuniary and prescriptive emotion managements in that they challenged nurses in their communication strategies, resulting at times in unequal exchanges. Bolton (2005), drawing on Goffman (1967/ 1982), emphasises that in most interactional situations there are 'traffic rules' in conjunction with feeling rules in operation. Families or other visitors, very much in contrast to nurses, do not need to follow those interactional 'traffic rules' (Bolton 2005) but can and do react spontaneously. Verbal abuse, as is also evident in the above excerpts, was the most common abuse to which nurses were subjected. Despite the government's launch of a 'zero tolerance policy' (Department of Health 1999), violence against health care staff is still common on both sides of the Atlantic (e.g. Beech 2001, Henderson 2003, Ferns and Chojnacka 2005, Anonymous 2005). Not surprisingly, abusive visitors lead to resentment amongst nurses. And yet, nurses remained calm and measured in their responses, taking time to 'resolve the problem' in question.

In sum, emotion management in communication emerged as a key factor in developing and maintaining a working relationship with families. In using strategies in accordance with prescriptive or pecuniary emotion management many nurses were able to maintain open communication channels with families to the benefits of patients, families and nurses' own well-being.

In arguing that not all emotion work within organisations is sold for a wage Bolton (2000b, 2005, Bolton and Boyd 2003) in particular has criticised Hochschild's one dimensional concept of emotional labour (Callaghan and Thompson 2002) for being too simplistic. As mentioned earlier, a greater conceptual clarity of emotionality in organisations is achieved by Bolton in distinguishing four types of emotion management: 'pecuniary' (emotion management for commercial gain), 'prescriptive' (emotion management according to organisational/ professional rules of conduct), 'presentational' (emotion management according to general social 'rules') and 'philanthropic' (emotion management given as a 'gift') (Bolton 2000b:156). Crucially, and in distinction to Hochschild, Bolton argues that many individuals can and do use all four forms of emotion management during their working day, drawing attention to the complexity of emotion management in organisations but also to the fact

that employees are social actors (e.g. Bolton 2000b, 2005). It is this understanding of nurses as social agents who are ‘active and skilled emotion managers in their own right’ (Bolton 2000a, 2000b, Callaghan and Thompson 2002, Lewis 2005) and the fact that emotion work is not always sold for a wage which seems more fitting within a nursing context in general, and my research context in particular. Further evidence of this position is offered in the next section.

Philanthropic and presentational emotion management

There are situations in nursing where the emotion work nurses offer goes beyond the aforementioned situations of emotion management. It is within the category of philanthropic emotion management where nurses offer additional gestures of caring that give ‘that little bit extra’ or goes ‘the extra mile’. This is the space where nurses not only live up to their professional standards but express their genuine interest in patients and families (Bolton 2005, Lewis 2005). Rather extraordinary examples were discussed in one of the focus groups.

F2: What about that woman we took up to (local department store)?

SK: An ICU patient?

F2: Aye.

F3: Or taken them down to (local area) for a coffee or whatever, ventilated ITU patient. The cobbles were a bit much though because I decided to walk. (*laughs*)

[]

SK: What kind of patients are you taking there?

F1: Someone like that lady.

F3: Longer term ventilated, yeh.

SK: Alright.

F3: Or somebody of the young home ventilation patients.

F1: For somebody that’s been in for ages and ages and ages, they just need a (pick up), a little something to show they’re making a bit of progress. Ahm and their family- everybody is down in the dumps and then something like that just, you know.

F2: Picks them up.

F1: Picks them up and says to them: 'no, I am going to get out of here' you know.

F3: Did you hear that they took someone for Christmas shopping over to (local department store)?

Nurses knew that I had intensive care experience and therefore there was an understanding during this discussion that I knew how much organising and co-ordination with other services is needed in preparing any kind of transport of ventilated patients. In addition to this, the department store in question had to, and had agreed to, admit this unusual party for a shopping spree after closing time. It is evident in these examples, that taking this 'long-term ventilated lady' out for her family's Christmas shopping or going down to a local coffee shop with a young long-term ventilated patient for a coffee, goes well beyond standard nursing care. In these instances nurses offered their patients and families this 'little bit extra' to provide hope at a time 'where everybody is down the dumps.' In emotional labour writing terms this form of emotion work is described as giving a 'gift' (e.g. Hochschild 1983, Bolton 2000a, Lewis 2005). Nurses offering a 'gift' to patients or families do not expect a return other than the contentment that their intervention 'made a difference' (McQueen 1997). This attitude was also evident in the above focus group when nurses recalled with satisfaction the family's joy, in particular the grandchildren of this patient, who, for obvious reasons, had not expected any Christmas presents or the boost families and patients got from venturing outside for a coffee.

The above examples are however exceptional in that more often the time for this kind of interventions is missing. Other examples which were mentioned across focus groups included a 'new born baby dangling over granny's face' which had a positive impact on this lady's tidal volume or bringing in the (small) dogs of a long-term patient. More frequently mentioned examples related to having time for bereaved families or involving family members in care activities with the clear underlying idea of supporting families during a time of uncertainty. In Chapter 7 I pointed out nurses' willingness to accept 'help' from children in looking after their ill family members.

Examples included 'writing down observational data', 'creaming hands' or 'washing a patient's face'. While some adult family members were involved in similar activities, others were offered the chance to participate in more extensive nursing interventions.

Involving families in care is not an easy undertaking. The bed bath is one example where the boundaries of presentational and philanthropic emotion management sometimes blur, challenging nurses in their responses to this tension.

D2: Well, (nurse's name) does the whole bed bath and things with relatives if the relatives want to. I think (.3) I would find that difficult. I had a patient actually once where the wife was watching me washing her husband, which I found really intimidating. And then- (.3) you know I wasn't doing anything wrong I just felt embarrassed like, that was her husband and part of her and I was washing him. And when I got to the groin area I thought: 'this is too much, I can't do this.' So I said to her: 'do you want to wash down here?' (*laughs*).' And she did. (.2) But I didn't know what else to do. I really did feel embarrassed. And then, from then on I think she was quite happy to be involved.

SK: So that was involvement but more because you didn't know how to tell her to go out?/

D2: /Well yeah./

SK: /Kind of thing?

D2: I think, I knew it was- I think I was speaking to (nurses' name) one day and watching (nurse's name) with relatives and I thought: 'oh, it's good to involve relatives.' So, I gave her the choice, eh, saying: 'I'm going to wash him now, do you want to stay or go?' and she said she'd stay. This was the first time. And I really didn't know what to do! I think I was bright red the whole time. (.3) If it was my partner there I'd be- I want to do it or he would prefer it done like this. But it worked out in the end and it was quite a nice breakthrough.

The nurse mentioned here is a senior nurse and quite exceptional in her incorporating approach to families. Involving families was seen as an intervention that provided the opportunity to prepare some families for an emerging caring scenario or as a coping mechanism during critical illness. In involving families, nurses alleviated feelings of 'uselessness' or 'being in the way' and offered instead a sense of 'having done something good' for the sick relative. This was underlined by one nurse saying that 'relatives are terribly enthusiastic about doing that (*creaming hands*) because it's one

of the few things that they can do'. It is this kind of daily supportive nursing care that takes place in ICUs but is rarely mentioned in connection with family nursing interventions.

The above excerpt is of interest because it demonstrates that involving families in care requires nurses to work hard on their own emotions in doing so. How hard this nurse had to work in order to cope with the above situation is evident in her comments about 'being embarrassed' or her belief that she was 'bright red the whole time'. 'Nursing in public' had challenged her to find a way around a societal norm of a non-touching culture (presentational aspect) and reconcile this aspect with a supportive nursing intervention required by the presence of the wife. It was out of the nurse's desperation that she asked the wife whether she wanted to be involved and so relieved herself from performing a very intimate aspect of nursing care 'in public'. While the wife's initial involvement was more by default, she did benefit in the long-term because from thereon 'she was quite happy to be involved.' In this context, 'choice' is a key concept in involving families. Like this nurse did, families need to be asked and given the choice of getting involved in care activities. Not all family members are keen to participate in caring activities (Bergbom and Askwall 2000, Azoulay et al. 2003) nor do all nurses embrace this challenge. The request by some family members to get involved and their offer to be involved in care by many nurses in this study supports the view that the reverse situation might also be true. Hammond (1995) who found that both families and nurses saw benefits in involving family members in care activities supports this view. In the end, involvement in care is a matter of negotiation. In this case, being confronted with the situation resulted 'in quite a nice breakthrough' and it is not unreasonable to expect that this nurse would involve families more often on a planned basis in the future.

What becomes apparent in all examples mentioned is the fact that emotion work within nursing is best conceptualised as a 'multi-situated system of activity' (Bolton 2000b). Within nursing, and contrary to Hochschild's (1983) belief, emotion work is not just a commodity sold for a wage. In the context of my data, ICU nurses clearly demonstrated that they were displaying faces which fitted the situation, suggesting that it was the situation which dictated the most appropriate emotional management style. I

therefore agree with those writers who argue that nurses are social agents which are 'active and skilled emotion managers in their own rights' (Bolton 2000a, 2000b, 2005, Callaghan and Thompson 2002, Lewis 2005) and suggest that this ability is a core competence for ICU nurses to protect their own well-being.

Closely linked to emotion management is a further aspect that aims at preserving the social order of a unit. It became obvious over time that there is, as Strauss and colleagues (1963) suggest, only one vaguely ambiguous agreed goal between differing professional or social groups in hospital settings and that is to return the patient to the outside world in a better condition that they were in hospital. Exactly how this goal is achieved is a matter of negotiation.

Negotiated order

While my focus in this study is not the patient but the family of the patient, the above statement still rings true. Both families and health care professionals worked on the same goal, namely the survival of the critically ill patient and did everything in their power to achieve this goal.

Negotiation, in this context, is understood as being 'one of the possible means of 'getting things accomplished' when parties need to deal with each other to get things done' (Strauss 1978:2). It is the presence of ongoing negotiations between groups that constitute processes which are crucial to the structural life in ICU (Strauss et al. 1964/1981). Within my data there is evidence of negotiations between nurses and physicians and nurses and families. With this in mind, I will now return to the discussion relating to functional uncertainty and giving information from Chapter 6.

Negotiated order: nurses and physicians

The negotiation around 'giving information' is a prime example for the processes of giving and taking and diplomacy that take place on a daily basis between nurses, physicians and families. 'Giving information' was described by nurses as an important part of their supportive work with families. Families' experiences with a critically ill family member evolved around issues of clinical and functional uncertainty pertaining to information (see Chapter 6). Giving information is not an unproblematic exercise

for nurses in ICU. It is a balancing act between clinical uncertainties, answers that can not be given because they are unknown and functional uncertainties and answers that must be adjusted to ensure a smooth running of the unit. This negotiation between 'what can be said' and 'who says it' is a crucial part of nurses' experiences with families as the following excerpts show.

D&E 1: Generally we're the first port of call for patient information about the patient ahm (.3) I mean that's my role with the family is to give them information about the patient and what's happening day to day with their patient.

D&E 2: I think it's also to interpret what's actually going on and what's actually said by everyone. And it's often a case of pitching it to the level the individual knows 'cause we tend to get to know relatives better than doctors do because if they're in all day, like some of them do stay, you get to know them after a while. And so interpretation of what's going on and our perception as to where we're going within sort of limited guidelines.

It is particular the concept of 'limited guidelines' that is of interest here. By the very nature of nursing, nurses are the group of health care professionals who have the most contact with patient and families. This is one of the reasons why nurses are seen, and see themselves, as 'the first port of call' and are often defined as a major resource for families in ICU (e.g. Leske 1992, Twibell 1998, VanHorn and Tesh 2000). Yet, giving medical information about the patient's health status is the responsibility of physicians. Nurses 'reiterate medical information' or 'explain what it all means' but they do not give first hand medical information, for example, scan or brain stem testing results. The information nurses provide differs and relates to the well-being of the patient, nursing aspects of critical illness, ICU environment, services (e.g. chaplaincy) or routines like visiting hours, ringing the bell for attention before entering the unit and so on. The position and role that nurses hold in the health care system hierarchy and the knowledge they have can put nurses in an uncomfortable situation with families.

D&E 2: And it's kind of taken that consultants are the ones, doctors are the ones who pass on major news events. If he had a CT scan and we know the result of that we can't say: 'well, CT Scans says that and that.' We have to keep quiet because the nurses- it's the role of the doctors to give information out first and foremost. And also because the result is perhaps (the result came down) verbally from the scan, that verbal result can change by the time it was formally looked at and deposited in the unit. So we could get the wrong viewpoint which isn't very

good. We try - we pride ourselves on complete honesty and openness, you know, it's our way. We're open about situations.

D&E 3: Sometimes you have to keep things to yourself because if you take someone for a scan you know that they've had a massive stroke and the problem is, you know you're going back in and the wife, the husband or whatever is saying: 'what did it show, what did it show' and of course you have to go then: 'well, I don't have the results yet.' I've done that quite often, I lie, you know.

D&E 2: Well we don't have results, the doctors got the results/

D&E 3:/ No, but if you were there, sat there and watched the scan you know exactly what went on, waited and chatted to people, you know.

SK: You have an idea, but you have to pretend you don't know?

Group: yeh.

In 'keeping quiet' nurses observed the 'limited guidelines' under which they had to operate because it was the 'role of the consultant or doctor' to pass on 'major news events'. It was apparent across focus groups that intensive care nurses are knowledgeable about the pathophysiology of diseases and its treatments, the various aspects of monitoring and its interpretation (e.g. ECG, ICP, and ventilation) and so on. I concur with Benner and colleagues (1999) when they stress that intensive care nursing is intellectually and emotionally challenging, requiring often immediate judgments and responses to life-threatening situation with very little room for error. In theory, it would be within the ability of ICU nurses to report back, in general terms, to waiting families scan results as described in the above situation and thus alleviate uncertainty.

In reality however a different scenario develops. In 'keeping quiet,' nurses observed professional boundaries since it is the 'role of the consultant or doctor' to pass on this kind of information. This type of evasive behaviour helps to maintain the different roles, function and responsibilities of nurses and physicians. It is, conversely, the case that professional boundaries are not static but dynamic and change over time; the extension of nurses' roles to include prescribing is one such example (Courtenay 2002, Nancarrow and Borthwick 2005).

In relation to negotiations within ICU, the context is of interest and as Maines points out 'these contexts are structural units that bound any particular set of negotiations, defining what is to be negotiated, by whom, in what manner, and for what purposes' (Maines 1977:253). While the given example does seem to underline status and power inequities that exist in health care to some extent, it more importantly hints at the team effort that is evident and necessary in intensive care to 'get things accomplished' (Strauss et al. 1963, Anspach 1997, Benner et al. 1999, Melia 2001) and functions to ensure a smooth running of the unit. It is the concept of 'structural units', namely medicine and nursing, and its negotiations around 'giving information' that accentuates health care as a multi-system, multi-professional endeavour and the hierarchy or order within these systems help to illuminate the function of the above described behaviour. Order, in the context of systems, is understood to be about 'the condition in which everything is in its proper place and performs its proper functions. It is about pattern.' (Pratt et al. 2001). In 'keeping quiet' nurses observed these differences in roles, responsibilities and functions between professions and so contributed to the social stability of their intensive care world. They negotiated their way through these 'limited guidelines' in the interest of all groups that 'need to deal with each other to get things done' (Strauss 1978:2).

The strategy of 'keeping quiet' puts nurses in an uncomfortable position with families because it conflicts with the unit's philosophy of 'being open and honest about the situation.' In saying that they, for example, 'don't have the result yet', nurses had to disregard their understanding of the importance of information for families to some extent. It is important to stress that families were not lied to, the information they asked for was just postponed till the appropriate person had time to disclose it. Nevertheless, this strategy troubled some nurses.

Negotiated order: families and nurses

Negotiations between nurses and families are nothing unusual. They are in fact a daily occurrence. Examples include families' participation in care activities or access to the patient and so on. However, families are complex and their dynamics can challenge nurses' negotiation strategies. The issue of 'who can be told what by whom' arose

particularly in families where there was a conflict in the background. The following excerpt serves as an example.

D2: I mean patients, we know their next of kin, who's is going to visit next. But the next of kin or a friend of the next of kin or whoever, they put little restrictions on who can come in: 'If so and so phones, don't tell him anything. If they phone, you can tell them something. If they come in to us, they can come in, but if they come in, they can't come in.'

And that is really frustrating because you're trying to figure out who is who and who can I tell and who can't I tell. Even though you're always protecting confidentiality, but- (*group: mmmm*) I feel that's not our place to be doing that all the time (D3: Yeh) and we tend to spend a lot of time going backwards and forwards and the finger gets pointed: 'oh, you must have said this and you must have said that.' (.3) I find it frustrating.

D3: I think we had a sort of situation where - (.3) a young guy came in and his mum didn't want his biological dad to know any information but his step-dad could. So when his dad rings up and he goes: 'I'm the dad' 'Are you the biological one or the step-dad?' I mean what position is that, you know. And imagine, being the biological dad hearing a nurse go: 'well actually I'm not allowed to give you any information you probably have to contact the mum.' I mean, if she didn't want him to ring then that's her situation/

D1: Yeh, she should-/

D3: / to deal with in a way./

D1: / she should explain to him and not put you in the position of saying-

D3: Yeh. I mean, make us aware that she's concerned about that, but then just make it a blanket: 'if anyone rings will you just say: can you contact the mum? She doesn't want any information' - not that we have to pick and choose which dad's allowed any information. And I mean if- I don't think anything did slip up but I mean I know I was just incredibly nervous about answering the phone to sort of any relatives. [] Because it's just a minefield of who should know and who shouldn't.

The analogy of a 'minefield' by one of the nurses in relation to releasing information to different family members is an interesting one. Here the complexity of families becomes evident through the dynamic within families, which in this case happened to be a conflict. From a nursing perspective, two main conflicts are apparent: firstly, the time needed to keep everybody informed and secondly, the ethical issue of including or excluding family members on the request of other family members.

It is evident in the above data, as it was in fact across focus groups, that nurses had 'to spend a lot of time going backwards and forwards' to keep all family members informed because 'they were not speaking to each other'. Sometimes the reason why they were not speaking to each other had nothing to do with a family conflict but related to family members' needs to 'hear it from' a physician or nurses. This was, for example the case, in the Asian family introduced earlier. At other times family communication problems were rooted in a family conflict. This increase in workload for nurses had an impact on their working conditions. From their perspective, as one nurse in a different focus group stated, 'time spent on the phone, is time spent away from the patient' and hence nurses were frustrated at what they saw as a hindrance to care (Beeby 2000).

Going 'backwards and forwards' to keep everybody informed redirected their attention away from the patient towards a conflict for which they, in the end, did not feel responsible. It is at this point that the 'vaguely ambiguous agreed goal' and the influence of presence of continual negotiations on the structural life on ICU (Strauss et al. 1963, 1964/1981) were brought to light. While the family focused on their critically ill family member and the needs of the family, nurses foremost focused on their patient and his or her needs in conjunction with preserving the social order of the unit. Viewed from this perspective, it was not surprising that nurses in focus groups discussed the idea of 'families name one person' who would function as a 'switchboard' that received and relayed information to all others. In theory, so the argument went, this would help nurses to know 'whom to tell what' and put the responsibility of informing other family members firmly onto families. This strategy of clearing the 'minefield' could potentially prevent 'slip ups' and any accusation of 'you must have said this and that', thus allowing nurses to control the social order of the unit to a much greater extent. It was however not practiced.

In addition, ethical issues arose if nurses needed to make value judgments in terms of who is or is not allowed to come into the unit on the opinion of a family member. Nurses were well aware that a family member's preference might be in conflict with what the patient would have wanted. In the above excerpt, the nurse raises the issue of imagining 'being the biological dad' and not being able to access information about

your son's critical illness. The discussion that followed made it clear that nurses saw both sides of the argument and were troubled by the request of this mother. Another example related to a dying patient and his sister; he had not spoken to her for many years and she now wanted to visit her dying brother. These are real issues with no easy answers which require nurses to negotiate with all concerned under difficult circumstances to find the best solution for all involved.

In situations like the above, the 'structural units' (Maines 1977), that is to say families and nurses, were bound by their different viewpoints in negotiating solutions. While family members made their decisions with their family in mind, nurses worked towards solutions that preserved the social order of the unit, but at the same time ensured, if possible, that they implemented whatever a family had decided. In the case of the biological dad, the wishes of the mother were obeyed, although as indicated, it did trouble nurses since they saw both sides of the argument.

It was not surprising that a number of nurses felt ill prepared to deal with these kinds of situations and were at times overwhelmed by them. There is agreement within nursing education in Scotland that families constitute an important part of nursing but there is currently no agreed conceptual framework on which such teaching is based (O'Sullivan-Burchard et al. 2002). This is in line with the responses of nurses in this study which underlined the fact that 'family' as topic did 'not really feature' in their pre-registration training. Nor is it at present part of post graduate education within intensive care or clinical appraisal forms. The focus remains very much on measurable skills such as 'technical competence'. Yet, it is here that emotional labour/management and negotiated order conceptually link. Nurses' ability to work on their emotions according to the present situation allowed nurses to negotiate with families not only in an attempt to support families during a critical illness episode but also to preserve the social order of the unit through their responses to the dynamics of their patient's families.

Summary

In this chapter I have identified 'nursing in public' as the core experience of ICU nurses with families. Contrasting the ICU world of families with that of nurses I

moved on to describe the nurses' experiences with families. Nurses' discussions of the open visiting policy and its impact underlined the tension between different interests of nurses and families in the context of organisational and structural aspects of health care.

In examining focus group interviews with nurses, issues of control over working time and patient care, adherence to unit rules and emotion management of nurses working with families were brought to light. Implementing an open visiting policy undoubtedly affected nurses' working time in that they lost the privacy to care. Family members who visited for prolonged times challenged nurses to develop a partnership in care approach, similar to the one that can be found in contemporary paediatric care (e.g. Casey 1993, 1995, Darbyshire 1993a, 1994, Coyne 1995). This challenge was not embraced by all nurses and strategies to distance family members and regain control over working time were evident in their arguments about the patient's right to privacy and the strategy of 'sending visitors to the waiting area.'

It emerged in family interviews and focus group discussions that not all families adhered to unit rules. At times this was due to the conflicting information families were given, while at other times families ignored unit rules. These situations created stress amongst families and nurses and led to a need for emotion management within the group of nurses. Nurses' ability to display 'a face' according to the situation helped to preserve the social order and hence ensured the smooth running of the unit, to the benefit of families, patients and nurses themselves.

Experiences with families in ICU were also influenced by the nurse's position within the health care hierarchy. Here I suggested that spatial distance or closeness of nurses to families influenced their view on families, in that more senior nurses saw 'families as their intervention unit' where other nurses saw 'the patient' as their focus of care. The nurse's perspective on this issue clearly had an impact on the scope of intervention and therefore on families' overall experiences in ICU.

CHAPTER 9

Discussion, Implications & Conclusion

We've talked on and on about resentment on the families' side but it's a big problem. Relatives are a big problem from our point of view and they cause a lot of resentment from our side of it. But nobody seems to care about that. Everybody cares about how the families feel rather than how we feel (Intensive Care Nurse).

You know, I really, really believe that people in intensive care, if the family can cope with being there and helping out, it can only be good for the patient, the family and staff (Susan, family 4).

It is one of the curiosities of intensive care that stories revolved around patients that were physically present but psychologically absent at the time of interviewing due to their need for ventilation and sedation. Interviews throughout this thesis bring out the differences in the experiences nurses and families had of each other in the context of critical illness. The admission of a patient to an ICU brings both groups together in one social space which is essentially the nurses' 'turf' (Heimer and Staffen 1998). Heimer and Staffen's insight pinpoints what this study is fundamentally about: the emergence of family care in intensive care nursing based on negotiations between nurses and families for the benefit of the patient, the family and the nurses.

My study presents evidence that underlines the importance of integrating families into ICU nursing and provides a rationale for such a move from a family and health care perspective. Policies, like the open visiting policy, are fundamentally important to allow families the flexibility to meet an array of competing needs from other family members, work and household chores during the critical illness. Further, staying near the patient helps to maintain the 'connectedness' (Walters 1995) between family members and patient and thus their existential bond. Staying near also alleviates family suffering and helps them understand what is happening at a time of clinical uncertainty which in turn builds trust in the health care professionals. Families' understanding and trust is paramount if health care professionals are to obtain consent for interventions and hence facilitates their management of the critical illness. The

question of whether there are long-term health benefits for family members arising from incorporating them into the care of the ill family member remains a subject for further research.

It is, however, equally true that focusing exclusively on the needs of families marginalises nurse's need for privacy when caring for critically ill patients. 'Nursing in public' emerged as the core experience of ICU nurses with families. This core theme initially became evident in nurses' discussions of open visiting policies and it emphasises the tension between the interests of nurses, families and the organisational and structural aspects of health care. It became apparent that families and nurses live in different worlds but in the same social space. For nurses the ICU represents an everyday workplace in which through becoming routine 'even traumatic events that occur there appear normal' (Chambliss 1996). Families, in contrast, enter a 'deeply weird' (Cassell 2005) world where everything is different and unrecognisable to them. This insight underlines the complexity of the context within which experiences of the same event are situated in the two groups and the resulting reciprocal influence of these experiences on both groups.

In examining focus group interviews with nurses working with families, issues of control over working time and patient care, adherence to unit rules and emotion management were brought to light. Implementing an open visiting policy undoubtedly affected nurses' working conditions in that they lost the privacy to care.

A partnership in care approach

Accepting the different interests and needs of nurses and families in relation to ICU patients, the question becomes one of how to balance the competing needs of families and nurses in a way that supports the functioning of both systems. Parallels between the 'partnership in care' approach evident in contemporary paediatric care (e.g. Darbyshire 1994, Coyne 1995, Callery 1997a, 1997b, Coyne and Cowley 2007) and the situation of nurses and families in ICU are evident. One consequence of an open visiting policy is the indirect establishment of family members as co-clients in ICU nursing. Co-clients have needs that ought to be met (e.g. Callery 1997b, Williams 2005) for two reasons: firstly, to alleviate suffering and support individual coping

strategies of family members and secondly, to preserve the social order which ensures the smooth running of an ICU. Family members who visited for prolonged times challenged nurses to develop a partnership in care approach simply by 'being there'. This challenge was not embraced by all nurses and strategies to distance family members and regain control over working time were evident, for example, in nurses' arguments about the 'patient's right to privacy' and the strategy of 'sending visitors to the waiting area.'

Coyne and Cowley's (2007) Grounded Theory study is one of the first to critically examine the philosophy of the 'partnership in care' approach from a parent's, child's and nurse's perspective. It is evident in this study that parents' participation in care is taken for granted by nurses while parents, although willing to participate, experienced boundary ambiguity. Parents were unsure how much care exactly was expected of them, while nurses saw themselves as 'fitting in' and filling the 'care gap' left by parents. It appears that part of the problem relates to a lack of communication between nurses and families and hence a lack of negotiation regarding boundaries between the parental and the nursing system.

While the situation in intensive care differs in that family members could not, and should not, take over care to the extent that happens in paediatric care, what is similar is the lack of communication and therefore explicit negotiation of system boundaries and the consequences this has for family care in ICU.

The boundary ambiguity families and nurses experienced in my study are reflected in the way families were perceived by nurses. Nurses with managerial responsibilities shared with families the view that the family member remains embedded in their family unit, while nurses at the bedside more often took the view that patients are connected to but independent of families (e.g. Hammond 1995, Hughes et al. 2005). This difference in perception has an immediate impact on the understanding of who constitutes the intervention unit in nursing. Families were at times confused and had to find out by 'trial and error,' which perception applied in a given situation. In essence, the bedside nurses saw 'the patient as the focus of care at the end of the day' (E5), while the nurses with management responsibilities defined the family as the nursing

intervention unit. I suggested in Chapter 8 that this difference is rooted in nurses' respective spatial distance to patients and families but also depends on the pathophysiological stability of the patient. Families being there 'all the time' simply had a different impact on nurses working exclusively or predominantly at the bedside. It was this group of nurses that faced the greater challenge in integrating families into their 'turf' (e.g. Heimer and Staffen 1998).

The emergence of family care

Many policy makers and nursing scholars (e.g. Hickey and Lewandowski 1988, Lynn-McHale and Smith 1991, Department of Health 1997, Hupcey 1998, Benner et al. 1999, Audit Commission 1999b, VanHorn and Tesh 2000, Williams 2005) argue for the promotion of a patient centred service in terms which imply the integration of families into care. In this context, the interface of the family and nursing systems in health care is of interest but little understood (e.g. Robinson 1996, Kirschbaum and Knafl 1996, Vaughan-Cole 1998). It is this lack of knowledge that Chesla and Stannard (1997) identified as an underlying cause for the current failure in the care of families in ICU (see Chapter 2). The shift from a paternalistic framework towards a collaborative approach to delivering health care is referred to as the 'new paradigm' (Faux and Knafl 1996). The continuing failure to achieve meaningful integration of families into health care raises the question as to whether policy makers, nursing scholars and practitioners have really grasped the scale of this paradigm shift. The paucity of research addressing issues of system interfaces and consequent lack of nursing interventions in this area suggest that they have not.

Kirschbaum and Knafl's (1996) study is one of the few that examined nurse-family interface issues. Working within the North American context, they identified such factors as expectations, trust, agency in decision making and communication that related to the overall satisfaction of relationships. These factors are echoed in Coyne and Crowley's (2007) UK based study, which identifies boundary ambiguity in both groups: families and nurses. These factors are also explicitly present in my family data and relate to the underlying mindset in managing clinical and functional uncertainty by families but are also reflected in nurses' experiences with families in ICU. Nurses frequently talked about the expectations families have or the trust that developed as a

result of a relationship between families and nurses, while families commented that ‘you have to trust them’ or ‘he is in safe hands here.’

The lack of conceptual clarity in relation to family, family nursing and health is evident in the lack of family nursing theories (e.g. Hartrick 1995, Segaric and Hall 2005). The family nursing models discussed in Chapter 2 draw attention to the different intervention levels available to nurses who wish to include families in nursing. Based on the idea that illness is a family affair, these models imply a distinction between *nursing* with an exclusive focus on the individual and *family nursing* which considers the patient and his or her family on different levels in its practice. The term ‘family nursing’ was introduced by Wright and Leahey but as early as 1994 they wrote that:

[w]e no longer subscribe to the term *family nursing* of which we once wrote (Wright & Leahey, 1990) because we no longer believe that family nursing is an appropriate term to define a baccalaureate nurse’s involvement with families. We do believe that this term has served a useful purpose within our profession, as it sensitized nurses to reinvolve families in healthcare. We now prefer the term *families in nursing*, as it captures an aspect of nursing at the generalist level (Wright and Leahey 1994:12 *Italic in original*).

Hence, the term had a political function but resulted in the current conceptual ‘muddle’ as to what is actually meant by it amongst nurses (e.g. Gilliss et al. 1989, 1991, Robinson 1995a, Segaric and Hall 2005). Viewed from this perspective, the lack of family nursing theories is perhaps not surprising. I concur with Wright and Leahey’s view that *families in nursing* refers to an important aspect of nursing but crucially it **is** still nursing. In this light, the usefulness of an exclusive family nursing theory must be questioned.

In everyday nursing, circumstances and competence dictate the level on which a nurse is able to function (Bozett 1987). In relation to circumstance, it has to be acknowledged that in intensive care nursing there are situations where the focus must remain entirely on pathophysiologically unstable patients in order to preserve their best chances of survival. This is substantiated in the example given by one of the ICU nurses in Chapter 8 (page 264). In reality - at the bedside - nurses adjust, and must

adjust, the level of family integration in reference to the actual health situation of the patient. With reference to competence, it seems obvious that nursing education must encompass *families in nursing* as well as the *individual in nursing*, as a pre-requisite to enable nurses to adopt the appropriate level in a given situation. This however, is currently lacking in nursing education in Scotland (e.g. O'Sullivan-Burchard et al. 2002).

In essence, the above insights underline that nursing is being-in-relation-with (Hartrick 1997, Hartrick-Doane and Varcoe 2005). Robinson (1996), examining the nurse-family interface, found that families affected by chronic illness did not focus on assessing their usefulness of nursing interventions but judged the outcome of interventions on the quality of the care relationship. She asserts that:

[] families offer an important reminder that relationships are not central to care, they *are* care (Robinson 1996:153, *Italic in original*).

While this thesis focuses on the family in nursing, the same arguments are valid in relation to individuals in nursing. It is through relationships that nurses and families come to know each other and knowledge is created that allows for the emergence of family care in ICU. While this is evident in the examples of supportive nursing interventions presented in Chapters 6, 7 and 8, the importance of caring relationships is often undervalued by many in the broad area of health care, including health care management and policy makers. This stance is reflected in performance evaluation forms which, as nurses in this study revealed, focus almost exclusively on technical skills.

The dynamic independence and interdependence of the family and nursing system is of importance in considering the practicalities and boundaries of a 'partnership in care' approach. In considering the impact of this approach on practice one has to remember that nurses are embedded in a complex health care system that is governed by rules, routines and structures which serve the preservation of the system itself. The hierarchical division of labour evident in health care is a result of this situation. Latimer (2000) points out that nurses do not have the privilege of organising their working day according to their needs but must do so in reference to other professions

within ICU and across the health care setting (see Chapter 8). At the same time, nursing is the only profession that is continuously present at the patient's bedside. Viewed from this stance, the resistance of some nurses to integrate yet another group, namely families, that makes demands on their time and the way they organise their work is understandable.

The emergence of negotiated family care

A negotiated order perspective is helpful in indicating a way to find a balance that supports the functioning of both systems. Negotiations, in this sense, are taken to mean strategies for 'getting things accomplished' (Strauss 1978:2), which in turn emphasises that intensive care is a team effort (Melia 2001). As discussed above, a peculiarity of intensive care is that stories revolve around often psychologically absent patients, leaving family members and nurses to look out for patients on their behalf. In the context of a health care organisation,

negotiations and the division of labour are rendered all the more complex because personnel [] share only a single, vaguely ambiguous goal. The goal is to return patients to the outside world in better shape (Strauss et al. 1963:154).

Families share this goal with nurses and health care professionals more generally which in turn defines the purpose of the ICU. Sharing a goal however does not mean having agreed on strategies how to achieve this goal. It is evident in this study that nurses are in a prime position to initiate and lead the integration of families into intensive care nursing. In fact, there are three reasons why it cannot be done by any other professional group. Firstly, family care is part of nursing since patients are embedded in their family units. Secondly, nurses are the health care 'insiders' while families are the 'outsiders'. This is reflected in power asymmetries between the systems 'family' and 'nurses' and consequently it is the more powerful group, namely nurses, that can initiate integration or change. And thirdly, nursing is the only health care profession that is based at the bedside around the clock and is affected by the presence of families directly. This is substantiated by nurses' data in this study which show that families cause considerable stress amongst nurses.

For this reason, it is this group within the health care system that must be in the driving seat of family integration. Nurses need to be given the education and hence tools to meaningfully integrate families into ICU care. The ability to do a family assessment and empowering nurses to negotiate with families about who is considered ‘family’ and thus control the flow of visitors in particular from large extended families is one example of how negotiated family care in ICU could support the social order of the unit. This would ensure the unit’s smooth running and balance the need of nurses for privacy while at the same time addressing family’s need to be near their loved one. Nursing, therefore has to take the leadership role in organising care that integrates the goals of both nurses and families to the benefits of patients, families and nurses.

In the following section a number of implications for education, policy and research raised by this study are identified.

Implications

Implications for education

It is the prolonged contact between nurses and families that requires nurses to clearly define boundaries and negotiate with families their integration into the care system. Participation in care can serve as an example. As discussed in Chapter 8, not all family members want to participate in care. The participation in care needs to be the choice of family members but the offer of nurses. One family in this study, frustrated at the nurse-dependent fluctuation of their care participation, made the useful suggestion that ‘there should be a place in the documentation where it’s written down if the family wants to help and what they want to help with. Families should be given a chance’. The inclusion of family comments in the care documentation requires a different type of documentation. A pre-requisite for this type of documentation is the nurses’ ability to conduct simple family assessments which in turn would require educational preparation in relation to families in ICU. Asked whether the ‘family’ had been an issue in their education, ICU nurses in this study revealed that it was not addressed in their pre-registration or post-registration education. Clearly, the lack of educational preparation of nurses to work with families is at odds with the political dictum of patient centred service. The family’s statement also reflects the boundary ambiguity

families in Coyne and Crowley's (2007) study experienced and supports the view that nurses must take on the leadership role in negotiating family participation in care.

Integration into care differs from participation in care. While the latter is an aspect of integration the former represents a difference in perception. From an integrational stance, recognizing that the patient is embedded in the family unit, illness is understood as a family affair. The need families have to be integrated into intensive care nursing is evident in the reported experiences which are at the heart of this thesis.

Consequently, as a minimum, the family in intensive care must be addressed in the specialist and postgraduate education of nurses working in critical care. Ideally, this further education would be based on prior knowledge gained in pre-registration courses.

Implications for policy

One outcome of this study is the insight that critical care is a family affair. Hence, it can be argued from a health care perspective, that there is an obligation to integrate families into ICU nursing. This view is strengthened if one reflects on the policy shift which moves care from the hospital into the community. Research has identified a lack of nursing knowledge within families who must care for often still severely ill patients at home (Whyte 1997a, Levy 2004, Foster and Chaboyer 2005). It was this shift in care provision that Whyte (1997a) referred to when she argued for the appropriateness of focusing on families in nursing as a means to support families in their care giving role. In relation to families of ICU survivors there is scant literature, suggesting that the impact of care-giving by the family after an ICU experience has just begun to be explored. Levy's (2004) study, however, shows that families struggle to cope with the care demands of former ICU patients. Whilst the overall increased survival rate of ICU patients is good news, these patients are now discharged 'quicker and sicker' (Chaboyer 2006) at a time when they are still care dependent in basic areas of daily living activities (bathing, use of the toilet, mobility and so on). In effect, care of dependent patients is transferred to families. Families however often lack the skills, knowledge or support to meet the care demands of former ICU patients (Levy 2004, Foster and Chaboyer 2005).

England and Australia, as discussed in Chapter 3, developed a critical care outreach service. In England, the service emerged from the Audit Commission's (1999b) report *Critical to Success* which evaluated the efficiency and effectiveness of critical care in England and Wales and the role was further developed in the Government's (DoH 2000) review on *Comprehensive Critical Care*. The latter document envisions the outreach role as sharing 'critical care skills with staff in wards and the community' and 'to use information gathered from wards and the community to improve critical care services for patients and relatives' (DoH2000:15). However, while services in both England (Valentine and Skirton 2006, Durham and Hancock 2006a, 2006b, Hancock and Durham 2007a, 2007b) and Australia (Chaboyer et al. 2005, Chaboyer 2006) address critical care issues of patients within and across the acute hospital they fail to link family care across acute and community services before and after ICU discharge. This is an aspect of the service that still needs to be developed across the UK and, it seems, elsewhere in the world.

Within the Scottish context, an expert panel report on '*Better Critical Care*' (SEHD 2000) explicitly rejected outreach teams and follow-up services since they would not influence the workload of ICUs, optimal patient care or bed requirements. Instead, the panel suggests a 'patient at risk' philosophy which focuses exclusively on severely ill patients in an effort to timely and appropriately admit these patients to an ICU. This reflects a rather simplistic view of a complex situation. As shown in this thesis the implications of critical illness go well beyond the clinical situation.

The approach of the Scottish expert panel also ignores emerging evidence which indicates the importance of an ICU aftercare service including patients and families (e.g. Clements 2000, Griffiths and Jones 2002, Angus and Carlet 2004) and calls by policy makers to design a patient centred service of which families are implicitly part. The importance of a family oriented nursing support service for families post ICU is further underlined by the shift in care provision from the hospital into the community, introduced by the Community Care Act 1990 and which draws deliberately on the family as care providers (Wasoff and Dey 2000). It is therefore paramount for policy makers to acknowledge the caring role of the family in the community and logically, their need to receive support in fulfilling that role. An outreach team that functions

across acute care hospital settings and reaches into the community would be ideally positioned in addressing long-term consequences of critical illness and thus support recovery of patients and families. Consequently, the process of integrating families into care should begin once a person becomes a patient, irrespective of the entry point in the system.

Implications for research

During the course of this research a number of interesting questions emerged which would be valuable to examine further in future research projects.

The lack of support and information material for families and children was troubling. Parents expressed their difficulties in knowing what to tell their children and some commented that it would have been helpful if there had been some 'leaflets' available (see chapter 7). This lack of support material for children is merely a symptom for what essentially represents the 'invisibility of children in the NHS' (e.g. Lachman and Vickers 2004). Focusing on the environment and with the exception of children's hospitals, it appears that children are literally designed out of health care spaces. A children's dental hospital department I know of, for example, informs users that 'toys and books are not allowed for hygienic reasons' (sic) – needless to say 'drinking and eating' is prohibited too. In GP surgeries 'play areas' (if provided at all) often appear to be an after thought – restricted to areas which could otherwise not be used (e.g. bay windows) and supplied with outdated toys and books. Yet, 'baby clinics' are regular activities taking place within this environment.

The invisibility of children results not only in the unavailability of age appropriate information but also functions as a rejection of children as part of families in public spaces. Adult control of public spaces (e.g. James et al. 1998, Morrow 2000, Vint 2005a), and this includes service providers like the NHS, is evident in the waiting areas of ICUs or other health care facilities. The lack of resources did not go unnoticed by participating children. Younger children like Fay (12, family 3) suggested that the unit needed a 'telly and more up-to-date magazines' to keep children entertained while waiting. Others suggested that games and books would help pass time. In this light, the absence of information material is not surprising if children are

not even acknowledged at a more basic level, namely that of providing simple entertainment for waiting times. In relation to children, the lack of information material was reinforced by nurses in Vint's (2005a, 2005b) study while Hughes and colleagues (2004) identified the same resource needs for adults. This then should be followed up in a family intervention study.

Further, the concept of 'ambiguous loss' as identified by some families in this study has the potential for a formal grounded theory. For this, further data should be collected across other conditions affecting the brain. Alzheimer disease, dementia or mental health conditions (i.e. Schizophrenia) as well as additional data on the long-term consequences of brain damage in patients and for their families would be useful in this respect.

A research project introducing family care into intensive care would also be desirable in an effort to develop a negotiated care approach with families and thus develop nurses' skills in working with families. This could be an action research project, underlining the leadership role nurses have in creating and implementing in the care of families.

And finally, the long-term outcome of ICU patients and their families has not been sufficiently researched. This is a largely unexplored area which needs attention in order to shed light on and develop an understanding of what happens after patients are discharged from ICU. In this study, women expected to take over caring responsibilities raising the issues of men's experiences facing the same long-term care situation (see chapter 7). In this context, Risman's (1998) work is of importance. She was interested in whether men are capable of a behaviour that is usually called 'mothering'. Her study sample included reluctant single fathers. These fathers were reluctant single parents due to the death of the mother or because their female partner had left, leaving the children behind. She concluded that men, should the necessity arise, can 'mother' and that children are not necessarily better nurtured by women than men (Risman 1998:70). Drawing on Risman's work, I assume that men would face similar issues in adjusting and dealing with critical illness as women did in this study. This however is a subject for further research.

Contribution to knowledge

There has been very little prior research that examines the experiences of families, young people's experiences with an adult family member in intensive care and nurses' experiences with families in this environment. The group approach taken in this study provides new insights into how families, young people in families process a critical illness event and how nurses' perceive families in ICU.

Consequently, this thesis contributes to knowledge in a number of ways. From a family perspective, the theoretical concepts of 'clinical and functional uncertainty' (Davis 1963/1991, Davis 1966) bring to light families' endurance of uncertainty during a critical illness and the implications these have on the family as unit. While clinical uncertainty has been the subject of nursing research, in the context of families as a group the discussed insights are predominately new. With regards to functional uncertainty, presented findings are novel in nursing research and no prior study exists that raises the issue of functional uncertainty in nursing.

Further, the exclusion of young people in family research in ICU is the norm and has been discussed at various points in this thesis. Accordingly, the inclusion of young people generated new insights and a better understanding of their experiences of critical illness in an adult family member. The study identifies strategies young people developed in managing the situation which have not been described before and can be used as building blocks for further investigations or interventions.

Equally, the inclusion of nurses as second group in this study allowed their voices to be heard in relation to their experiences with families. The notion that nurses need privacy to care but are 'nursing in public' is a new insight. As argued, this insight challenged current policies of a patient centred health care service which marginalises the needs of nurses caring for critically ill patients.

In essence, the new knowledge connections which emerged in this thesis are based on major themes that are grounded in the experiences and perspectives of families, young people in these families and nurses during a time of critical illness. The resulting 'emergence of negotiated family care in intensive care' approach as a means to balance

the needs of both, families and nurses, is suggested as a way forward and is the main knowledge contribution of my thesis in the area intensive care nursing.

Conclusion

In 2004 over 9500 critically ill patients were admitted to intensive care units in Scotland alone (SICS 2005). Despite the high numbers of ICU admissions little is known about the short and long-term impact of critical illness on patients, their families and particularly their children. Therefore, many of today's children have the experience of visiting a family member in ICU. However, as was pointed out in Chapter 2, families experience critical illness as a traumatic and life changing event. Moreover, there has also been little research into the experiences of nurses working with families in ICU.

The findings of this study draw attention to the way families and nurses co-construct the care environment. Qualitative group interviews led to novel insights and important findings firstly, identifying the strategies families employed in dealing with clinical and functional uncertainty (Davis 1963/1991, 1966) and secondly, in revealing the constant negotiations of nurses with families in an attempt to control their work environment and create space for undisturbed caring.

The findings of this study are also of interest to professionals working with children and young people. Including children in family interviews is surprisingly rare (e.g. Hill and Tisdall 1997, Qvortrup 2002) and therefore my findings offer novel insights into how young people process a critical illness event in their families. These findings point towards possible interventions to support young people during a time of uncertainty.

Further, the findings of this study are of interest to policy makers and practitioners involved in designing and delivering health care. The suggested 'partnership in care' approach which is based on negotiations between stakeholders under the leadership of nurses has implications for the education of nurses. As discussed above, many health care policies argue for a patient centred service. Yet, this paradigm shift is currently not reflected in the education of health care professionals.

In conclusion, this study fills a significant knowledge gap by showing how families process critical illness and how nurses view families in an ICU. The findings suggest a ‘negotiated family care in intensive care’ approach as a means to balance the needs of families and nurses.

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APPENDIX 1

Development of young people's consent and assent forms

Introduction

Including children in research raises a number of methodological and practical issues as discussed in depth in chapter 3 and 4. One practical issue relates to providing information and consent or assent forms that are geared towards the young people in question. While the provision of information and the obtaining of consent or assent prior to the inclusion of young people in research are legal requirements (e.g. Lindeke et al. 2000, Masson 2000, 2004) little has been published about the development of these forms. There exists a paucity of literature which could provide guidance on these documents for researchers wishing to include young people in research.

Realising this predicament, I raised the issue with lecturers of the '*Listening to Children*' course that I attended at the University of Edinburgh as part of my PhD education. One of the lecturers suggested contacting Professor Priscilla Alderson for further information. I followed this suggestion and Professor Alderson very kindly sent some examples she had collected from her own and other researchers' studies with children. Unfortunately, this letter was lost within the University's post, ending up in a different department and was only sent on some six months later. By this time I had already developed my forms from scratch and ethical approval had been granted.

In the following I describe the process by which I developed the forms and the changes they underwent as a result of an evaluation with young people prior to use in the study.

Research process

Developing information leaflets and consent forms

Lindeke and colleagues (2000) assert that there are few guidelines that help researchers to design developmentally appropriate information and consent forms for children. Writing information material or consent forms that are appropriate for the age group of interest is challenging from an adult perspective. While I used Lindeke and colleague's (2000) model assent form as guide in developing my material for this study, it was felt

that only young people themselves would be able to assess how appropriate this material actually is.

It was for this reason that I set up a series of discussion groups with young people to evaluate the usefulness, readability and ease of understanding of my study material. The discussion groups followed the principles of focus groups as discussed in Chapter 3 and 4. Accordingly, group size did not exceed six participants, participants remained in their peer group, participation was voluntarily and food and drink was provided for the discussions. These discussions were not tape-recorded but detailed notes were taken. As a result of these discussions a number of suggestions on layout and word choice were included in the final documents. I also concluded that two separate forms were needed: one for younger children and one for teenagers.

Research setting

The research setting was a school in Central Scotland encompassing junior and senior school pupils. The school is co-educational up to year 3 after which the school becomes a single sex (girls) school. With around 500 pupils this is a small school in comparison to other schools in the same city.

Gaining access

Accessing a research facility is time consuming and time pressures within the defined time limits for degree research challenged me to find a compromise that would allow evaluation of forms with young people in the relevant age groups to be carried out quickly. The school in question was chosen because I already had a relationship with it which simplified obtaining access and thus reflects a pragmatic choice on my part.

The Principal of the school was contacted in writing. The study and the need to evaluate the forms that would be used with young people were explained. Subsequently my request to access pupils in Primary 6 up to Senior 4, since these year groups reflected the age range of young people I intended to include in the research, was approved and passed on to the Deputy Principals of the Junior and Senior schools. The Deputy Principle of the Senior School was named as my contact person. A meeting was set up in which I presented my study and introduced the information, consent and assent forms

which were to be evaluated. Possible dates, times and locations in the school for the focus groups were discussed and agreed.

Recruiting participants and consent

The Deputy Principle of the Senior School wrote to parents on my behalf asking parents for permission to include their daughters should they chose to participate. This is a common procedure in this school by which parents are informed about a study and thus given the opportunity to raise any concerns they may have. However, written consent is usually not obtained and was not obtained on this occasion. Parents were informed that the discussion would take place during their daughter's lunchtime and that food as well as drinks would be provided by the researcher.

The actual recruitment was achieved through teachers. Teachers asked pupils if they had an interest in participating and those indicating an interest were informed of time, location and day.

On the day of the group discussions I asked pupils again if they felt happy to participate, confirming myself that this reflected their free choice before starting the group discussions.

Sample description

Overall 27 pupils participated in group discussions (see Table 3). All participants were girls ranging in age between 11 and 16 years. This age range reflects pupils in their school education from Junior 6 up to Senior 4. The discussion groups were held in June 2002 nearing the end of a school year. As a result, I was unable to arrange a discussion group with Senior 2 pupils due to their various end of term activities (e.g. sports day, educational visits). In Scotland, children turning four in January or February can start school the same year if parents wish their child to start. As a result of this policy, the age gap within a class can vary up to almost a year. This knowledge is of importance in considering a child's level of understanding which, naturally, develops over time. An overview of participants' age and school year distribution is presented in Table 3.

Table 3: Overview of participating young people in evaluating research forms

Group	Age 11	Age 12	Age 13	Age 14	Age 15	Age 16
Junior 6	5					
Junior 7	1	4				
Senior 1		4	2			
Senior 3				2	4	
Senior 4					4	1
Total	6	8	2	2	8	1

Group discussions

The sessions started with my introduction and an explanation why I was interested in their views regarding the developed material. The discussion settings were locations within the school. It was therefore important to distinguish myself from authority figures such as teachers. I pointed out that I was not a teacher and offered that girls should use my first name if they felt comfortable in doing so. This strategy was used to set participants at ease about raising possible positive and negative points in their evaluation of the material.

Following a little informal chat about school life, the weather and so on the information leaflets were handed out. Participants were asked to read this material with the request to comment on how easy or difficult it was to understand and how easy or difficult it was to read. Answers were used to trigger a discussion seeking suggestions for possible improvements to the material.

As an arbitrary measure I had set a reading time limit of five minutes in order to get an idea how long it would take young people to read the leaflets. This time limit was not

known to participants. It was assumed that if the material was too long or too tedious to read the young person's interest would be lost, leading to non-participation. In fact, none of the pupils needed more than three minutes to read through the material, while some read it more than once within that time.

Use of language and understanding

Information material for specific age groups needs to be respectful of the targeted age group, on a level that members of this age group can understand and must not be patronising in tone. Each document also has certain required content. Consent forms, for example, need to include information such as the intention to record the conversation, the right to confidentiality and anonymity, what will happen with the data and the dissemination of research.

Consent to participation can only be valid if it was given freely and after the potential participant has considered the details of his or her participation. In taking young people seriously it is obvious that the same details must be brought to a young person's attention before a decision is taken. The challenge then is using language in a way that enables a young person to come to an informed decision.

Initially, I had developed one information leaflet and one consent form for all children across age ranges. It became evident in group discussions that younger children required a different form of language in order to feel comfortable with the material.

Junior 6 pupils for example suggested using the phrase 'If it is OK with you' because it reflected their every day use of language. This year group was also comfortable with the terms mum and dad. In fact, Junior 6 and 7 pupils suggested that 'mum and dad' are 'friendlier' terms than 'parents'. In contrast, almost all senior pupils pointed out that they would not use 'mum' or 'dad' but the term 'parent'.

Confidentiality was one of the terms I specifically asked pupils to define for me. In all groups pupils could give an explanation in their own words such as 'you are not supposed to discuss things with others', 'that means to keep something secret' or 'you don't tell others what you talked about' in describing the term. Asked if this word should be substituted Junior pupils in both groups argued that it should remain but

maybe should be a 'little bit more explained'. Again, Senior pupils affirmed that they used the term themselves and that there was no need for substitution. As a result, confidentiality in the children's assent form is explained while in the teenager's form it is assumed that it is understood.

Layout of forms

The initial layout of the forms used paragraphs without any additional headings. Junior 6 pupils suggested headings to make reading and orientation within forms easier. The forms were amended before being discussed again in Junior 7 and older year groups. Younger participants confirmed that headings made reading easier, while older participants assumed that it would make reading easier for younger children but did not require it for themselves.

A number of younger girls suggested decorating the forms with borders and flowers or using different colour for the headings. These suggestions were not included in the final version since the forms fulfil a particular information requirement. I had included the 'group' drawing, which in its original version is coloured, with the intention to make the forms more attractive to young people. It is unclear whether the colourful drawing prompted the above mentioned suggestions or whether these reflect an age or gender difference.

Participants were also asked whether the font size was sufficient. Again, younger participants argued that it was easier to read something that had 'bigger letters'. As a result, the font sizes differ according to age group in the final material.

Conclusion

In conclusion, participants described the forms as 'fair' because they provided the potential participating young person with a choice. The group discussions helped me to realise that I had written material that in its language was geared towards younger children but in its layout reflected the requirements of older children. Senior pupils found the language used too patronising and the final wording was chosen with their help.

Junior school pupils also made some very useful suggestions for improving the readability of the forms which is reflected in a different font size, language use and layout in the final material.

Perhaps as a result of these group discussions and the subsequent amendments, the participating children in the study reported no problems with reading or understanding the material.

APPENDIX 2

Consent and assent forms



University of Edinburgh

School of Nursing

Children's Assent Form

Study title: Families' Experiences in Intensive Care Units

Sometimes a parent gets very sick and needs to go to hospital to a special ward - an Intensive Care Units. On these units there are a lot of people looking after your mum/ dad. Amongst those people are nurses. I am a nurse and my name is Susanne.

Talking to children

If it is O.K. with you, I would like to ask you some questions about how it was for you when mum/ dad was very sick and needed special care. Your other parent will be with you and I will ask them some questions, too. Talking to children and listening to what they have to say about the time when one of your parents was in Intensive Care will help nurses to learn how to take better care of families.

Tape recording our conversation

I will also tape-record our conversation. This helps me to think through what I was told by your family. When I am done with all that thinking those tapes will be destroyed. This is a normal procedure in research. It helps me to keep the things I was told confidential. Confidential means that I will tell nobody who you are or use your real name in any publications, for example, journal articles or reports after finishing my research project.

If you have any questions about this please ask me. I will answer them as best as I can. Signing this form means that you have read and understood this letter. It also means that you want to answer my questions.

Can I change my mind?

Should you change your mind and not want to talk about this time anymore, that is O.K. too. You don't have to if you don't want to. Just tell your mum/ dad or me and I will stop asking you questions.

How can I contact you if I have any questions?

If you forgot something to ask me but really need to know before you can make up your mind you can phone me under (phone number) or send an e-mail to: suse@family-nursing.com.

Child:

Researcher:

Date:



University of Edinburgh

School of Nursing

Teenager Assent Form

Study title: Families' Experiences in Intensive Care Units

Sometimes a family member gets very sick and needs to go to hospital to a special ward - an Intensive Care Unit. On these units there are a lot of people looking after your sick parent. Amongst those people are nurses. I am a nurse and my name is Susanne.

If it is alright with you, I would like to ask you some questions about how it was for you when one of your family member was very sick and needed special care. Your parents will be with you and I will ask them some questions, too. Talking to children and young people, listening to what they have to say about the time when one of your family members was in Intensive Care is very important and can help nurses to learn how to support families in such situations.

I will also tape-record our conversation. This helps me to think through what I was told by your family. For confidentiality reasons I will destroy all tapes after finishing the study. This is a normal procedure in research.

I will also not use your real name in any publications, for example, journal articles or reports after finishing my research project.

If you have any questions about this please ask me. I will answer them as best as I can. Signing this form means that you have read and understood this letter. It also means that you want to answer my questions.

Should you change your mind and not want to talk about this time anymore, that is alright. too. You don't have to if you don't want to. Just tell your parents or me and I will stop asking you questions.

If you forgot something to ask me but really need to know before you can make up your mind you can phone me under (phone number) or send an e-mail to: suse@family-nursing.com.

Participant:

Researcher:

Date:

**University of Edinburgh
School of Nursing**

Consent Form Adult Child

Study title: Families' Experiences in Intensive Care Units

This is to certify that I,.....(name printed) hereby consent to participate in the interview study conducted by Susanne Kean (PhD student).

I understand that the purpose of this study is to explore the experiences of families in intensive care units. I understand that the interview is a family group interview. The interview will take place at a venue and time convenient for us and after my parent has been in intensive care at least 3 days. During the interview, which will last a maximum of one hour, questions will be asked regarding our experiences of having a family member in intensive care.

Participation in this study will have no direct benefits for my family or me. However, the information gained in this study may help critical care nurses in their continuing development of practice in the care of families in intensive care units.

I understand that participating in this study will not result in any risks to my health.

I understand that the interview will be tape-recorded. This recording will be used for research purposes only and tapes will be destroyed after completion of the study.

I understand that if I do not take part in the interview study, my refusal will not have any negative consequences for my parent or any other member of my family. I also understand that I am free to refuse to answer specific questions without giving any reason and am free to withdraw my consent or participation at any time.

I understand that it is likely that findings will be published after completion of the study and that I or any other family member will not be identified by name in any subsequent publication. A copy of the findings will be available to participants at their request after completion of the study.

I was given the opportunity to ask any arising questions and these questions have been answered to my satisfaction. Should I have any further questions or concerns the researcher (Susanne Kean) can be contacted at (phone number) or suse@family-nursing.com .

Participant:

Researcher:

Date:

University of Edinburgh



School of Nursing

Parental Consent Form

Study title: Families' Experiences in Intensive Care Units

This is to certify that I, the parent, hereby consent to the participation of our child.....(name printed) in the interview study conducted by Susanne Kean (PhD student).

I understand that the purpose of this study is to explore the experiences of families in intensive care units. I understand that the views and experiences of children form part of the overall family experience and are important to enhance nursing care towards families. I discussed the proposed study with our child and it is his/ her free will to participate in the interview. The interview will take place at a venue and time convenient for us and after my spouse/ partner has been in intensive care at least 3 days. During the interview, which will last a maximum of one hour, questions will be asked regarding our experiences of having a family member in intensive care.

Participation in this study will have no direct benefits for my family or our child. However, the information gained in this study may help critical care nurses in their continuing development of practice in the care of families in intensive care units.

I understand that participating in this study will not result in any risks to our child's health. Our child was given an information leaflet explaining the study and possible after care support should our child request this. A phone card was provided with the information leaflet.

I understand that the interview will be tape-recorded. This recording will be used for research purposes only and tapes will be destroyed after completion of the study.

I understand that if I do not take part in the interview study, my refusal will not have any negative consequences for our family. I also understand that my child/ren is/ are free to refuse to answer specific questions without giving any reason and is/are free to withdraw his/ her consent or participation at any time.

I understand that it is likely that findings will be published after completion of the study and that our child/ren or any other family member will not be identified by name in any subsequent publication. A copy of the findings will be available to participating families at their request after completion of the study.

I was given the opportunity to ask any arising questions and these questions have been answered to my satisfaction. Should I have any further questions or concerns the researcher (Susanne Kean) can be contacted at (phone number) or suse@family-nursing.com .

Parent:

Researcher:

Date:



University of Edinburgh

School of Nursing

Consent Form

Study title: Families' Experiences in Intensive Care Units

This is to certify that I,.....(name printed) hereby consent to participate in the interview study conducted by Susanne Kean (PhD student).

I understand that the purpose of this study is to explore the experiences of families in intensive care units. I understand that the interview is a family group interview including my child/ children aged 10 years⁹ or over. The interview will take place at a venue and time convenient for us and after my family member has been in intensive care at least 3 days. During the interview, which will last a maximum of one hour, questions will be asked regarding our experiences of having a family member in intensive care.

Participation in this study will have no direct benefits for my family or me. However, the information gained in this study may help critical care nurses in their continuing development of practice in the care of families in intensive care units.

I understand that participating in this study will not result in any risks to my health.

I understand that the interview will be tape-recorded. This recording will be used for research purposes only and tapes will be destroyed after completion of the study.

I understand that if I do not take part in the interview study, my refusal will not have any negative consequences for my family member or any other member of my family. I also understand that I am free to refuse to answer specific questions without giving any reason and am free to withdraw my consent or participation at any time.

I understand that it is likely that findings will be published after completion of the study and that I or any other family member will not be identified by name in any subsequent publication. A copy of the findings will be available to participants at their request after completion of the study.

I was given the opportunity to ask any arising questions and these questions have been answered to my satisfaction. Should I have any further questions or concerns the researcher (Susanne Kean) can be contacted at (phone number) or suse@family-nursing.com.

Participant: _____

Researcher:

Date:

⁹ If applicable see additional consent form for your child/ children



University of Edinburgh

School of Health in Social Science

Nurse Consent Form

Study title: Families' Experiences in Intensive Care Units

I,.....(name printed) consent to participate in the focus group discussion conducted by Susanne Kean (PhD student).

I understand that the purpose of this study is to explore the experiences of families in intensive care units from a nurses' viewpoint. I understand that the focus group is a nurses' group discussion, will not last longer than one hour and will be held at a time and location convenient for me.

Participation in this study will have no direct benefits for me. However, the information gained in this study may help intensive care nurses in their continuing development of practice in the care of families in intensive care units.

I understand that the interview will be recorded. This recording will be used for research purposes only and audio files will be destroyed after completion of the study.

I understand that if I do not take part in the focus group discussion, my refusal will not have any negative consequences for me. I also understand that I am free to refuse to answer specific questions without giving any reason and am free to withdraw my consent or participation at any time.

I understand that it is likely that findings will be published after completion of the study and that I will not be identified by name in any subsequent publication. A copy of the findings will be available to participants at their request after completion of the study.

I was given the opportunity to ask any arising questions and these questions have been answered to my satisfaction. Should I have any further questions or concerns the researcher (Susanne Kean) can be contacted at (phone number) or suse@family-nursing.com .

Participant:

Researcher:

Date:

APPENDIX 3

Study information leaflets for young people, adult family members and nurses



Children's Information Sheet

Sometimes a parent gets very sick and needs to go to hospital to a special ward – an intensive care unit. On these units there are a lot of people looking after your sick parent. Amongst these people are nurses. I am a nurse and my name is Susanne. I would like to talk to you and your family about the time when one of your parents was in intensive care.

Before you make up your mind whether you would like to talk to me, I would like to give you some information what this is all about. If there is anything that is not clear or if you would like more information, please ask me. I will try and answer all your questions as best as I can. There is no rush, please take time to decide whether or not you wish to take part.

Study title: Families' experiences in intensive care units

What is this study about? I would like to ask you and your family some questions about how it was for you when mum/ dad was very sick and needed special care.

Why is this study being carried out? Talking and listening to children and families to what they have to say about the time when one of your family was in intensive care will help us nurses to learn more how to take better care of families.

What do I have to do? If your family decides to take part in this study I will arrange a meeting with your parent. We will talk all together for about one hour. I would like to tape record our conversation (with your permission). This will help me to think through what I was told by you and your family.

However, after I am finished with this thinking through the tape will be destroyed. This is a normal process in research and helps me to keep the things I was told by families confidential. Confidentiality means, that I will not tell anyone who you are or use your real name in any publications (for example, reports after the study is finished).

Do I have to take part? No – you don't. It is entirely up to you to decide whether or not you wish to be part of this study. If you decide to take part you can change your mind if you decide you don't want to talk about this any more.

How can I contact you for further information? If you have any further questions, please contact me (Susanne Kean) at (phone number) or e-mail suse@family-nursing.com



Teenager Information Sheet

Occasionally a parent gets very sick and needs to go to hospital to a special ward – an intensive care unit. On these units there are a lot of people looking after your sick parent. Amongst these people are nurses. I am a nurse and my name is Susanne. I would like to talk to you and your family about the time when one of your parents was in intensive care.

Before you make up your mind whether you would like to talk to me, I would like to give you some information what this is all about. If there is anything that is not clear or if you would like more information, please ask me. I will try and answer all your questions as best as I can. There is no rush, please take time to decide whether or not you wish to take part.

Study title: Families' experiences in intensive care units

What is this study about? I would like to ask you and your family some questions about how it was for you when one of your parents was very sick and needed special care.

Why is this study being carried out? Talking and listening to children, young people and families to what they have to say about the time when one of your family members was in intensive care will help nurses to learn more how to support families in similar situations.

What do I have to do? If your family decides to take part in this study I will arrange a meeting with your parent. We will talk all together for about one hour. I would like to tape record our conversation (with your permission). This will help me to think through what I was told by you and your family. In order to keep the conversations confidential all tapes will be destroyed after the study is finished. This is a normal process in research. It is likely that I will write some reports about the study results. In this case I will not identify you or your family or use your real name in any publications (for example, reports).

Do I have to take part? No – you don't. It is entirely up to you to decide whether or not you wish to be part of this study. If you decide to take part you can change your mind at any time without any consequences for you.

How can I contact you for further information? If you have any further questions, please contact me (Susanne Kean) at (phone number) or e-mail suse@family-nursing.com



Family Information Sheet

Dear family member,

Your family is being invited to take part in a research study. However, before you decide whether to accept it is important that you know what the study is about, why it is being undertaken and what it will involve. Please take the time to read this information and discuss it with your family or any other person you chose to. Please ask the researcher if there is anything that is not clear or if you would like more information. There is no rush; please take time to decide whether or not your family wishes to take part.

Study title: Families' experiences in intensive care units

What is this study about? The study will explore families' experiences in an intensive care unit after one family member has been on the unit for at least 3 days.

Why is this study being carried out? This study aims to help nurses to have a better understanding and gain new knowledge in the care of families in intensive care units.

At present, there is only very limited knowledge available about the experiences of families in intensive care units. Previous research has focused very much on individual adult family members, thus excluding children from the family. However, since critical illness does affect the whole family it is important to understand the whole family's experience. This is also the reason why your family is being invited to participate since your family includes children age 10 years or over.

What do we have to do? If your family decides to take part in this study the researcher will arrange an interview date after the receipt of your signed consent forms. The interview will take place at a time and location convenient for you. The interview will last a maximum of one hour and will be tape recorded (with your permission). The recording will be used for research purposes only and tapes will be destroyed after completion of the study.

Confidentiality Everything your family says will be kept confidential between your family and the researcher. Your family name will not be attached to the tape nor will any individual family member or family be identified in any subsequent publication of study results.

Do we have to take part? No – you don't. It is entirely up to your family to decide whether or not you wish to be part of this study. If you decide to take part you can change your mind and withdraw at any time without giving a reason. Your decision will not affect the standard of care received by your family member now or in the future.

Are there any possible benefits for my family in taking part? Taking part in this study will not result in direct benefits for your family or any member of your family. However, participation and the information gained in this study may help intensive care nurses to better support families in a similar situation to yours in the future.

Are there any possible disadvantages in taking part? It is entirely up to your family how much information you are prepared to share with the researcher during the interview. You can refuse to answer any question without giving a reason. Should any member of your family wish to raise a particular issue outside the research interview, there is a counselling service available within the Hospital Trust and your children will be given a helpline number after the interview.

Who is responsible for this study? This study is undertaken as part of a Doctoral research project at the University of Edinburgh. The researcher (Susanne Kean) is a qualified nurse with intensive care experience. Prof. Kath Melia and Dr. Dorothy Whyte, of the University of Edinburgh, supervise the study.

Has this study been reviewed? Yes – the study has been reviewed and approved by the Lothian Ethics Committee.

How can we contact the researcher for further information? If you have any further questions, please contact Susanne Kean at (phone number) or e-mail suse@family-nursing.com

Should you wish to contact one of the study's supervisors (Prof Kath Melia or Dr. Dorothy Whyte), please contact the School of Nursing, University of Edinburgh, general enquiries (phone numbers) or e-mail Nursing@ed.ac.uk
Alternatively you can contact the independent advisor to this study, Ms Hazel MacKenzie, Royal College of Nursing at (phone number) or e-mail hazel.mackenzie@rcn.org.uk.



Focus Group Information

Families' Experiences in Critical Care Units: the Nurses' Perspective

A number of you will be aware that I am currently conducting a PhD study exploring families' experiences in intensive care. The study is organised in two phases. **Phase 1** explored families' experiences in ICU. The study is now moving into **Phase 2** and will be exploring ICU nurses' perspectives on families in the unit.

It is evident from the literature and my family data that most nursing interventions with families take place at the bedside. Therefore, nurses' perspectives on families' experiences of the ICU are important to my study because they influence the support provided to families.

I am specifically looking for nurses who have at least 6 months critical care nursing experience (HDU experience would count towards these 6 months).

Focus Group Discussions will be held on **Mondays** between **3.45 – 4.45 p.m.** in the units' seminar room. The discussion will evolve around your views/ perceptions of families' experiences in intensive care.

The discussions between the group and the researcher are **confidential**. For data analysis purposes it is necessary to record discussions. However, participant names will not be identified, attached to any transcript or any subsequent publication. Audio records will be destroyed after completion of the study.¹⁰

Snacks and drinks will be provided.

Should you need any further information, please don't hesitate to contact me directly (phone 0131 557 9943 or e-mail: suse@family-nursing.com).

Your support for the study is very much appreciated and I am looking forward seeing you!

Susanne Kean

¹⁰ The study is supervised by Prof. Kath Melia & Dr. Dorothy Whyte. If necessary, both can be contacted through the Nursing Studies Department (phone: 0131 650 3889 or 650 3891). The Anaesthetics/Dentistry/Surgery Research Ethics Committee of the Lothian Research Ethics Committee has granted **ethical approval**.

APPENDIX 4

Examples of recruitment and demographic data sheets for ICU nurses

Study: Families' experiences in Intensive Care

Phase 2: The nurses' perspective

Focus Groups Discussions

I am looking for 5 – 6 participants for the following Focus Groups Discussions. The discussion will evolve around your views/ perceptions of families' experiences in intensive care.

Thank you for taking part.

Susanne Kean

No	Date	Name	Grade F/ senior E
1			
2			
3			
4			
5			
6			

Location: ICU Seminar room

Time: Mondays, 3.45 – 4.45 p.m.

Snacks and drinks (hot & cold) will be provided

Study: families' experiences in Intensive Care Units

Focus Groups

Nurses' Demographic data Sheet

Name	Age	Gender	Lengths of ICU experience in years	Grade

APPENDIX 5

Examples of interview topic guides

Family 3: Interview questions - prompts & probes

- Like to talk about your experiences of having a family member in intensive care.
- So – I'd like to ask you how it is for you of having a dad in intensive care/ hospital.

- Genogram, Hobbies, favourite subject in school, Friends
- Can you tell me a little bit about what happened to your dad?

- Can you tell me about the first time you visited your dad in intensive care/ hospital? (Children's term?!)
 - How was it for you?
 - Can you remember what you thought when you saw your dad for the first time?
 - Where things explained to you? Who explained them?

- Who do you talk to about dad being ill/ in hospital?
- What does it mean for your family to have a family member in ICU?
 - Effect on daily life/ routine
 - Waiting time
 - Is there anything special you do to help your mum? What would that be?
 - For whom in the family is it most difficult that dad is in hospital?
- Who in the family is the most affected by your husband's hospitalisation?
 - How does he or she show it?

- What is the family's greatest concern or challenge regarding your husband's hospitalisation at this point in time?
 - Who helps you with this challenge? (Social support network)
 - Is there someone you can talk to?

- How can nurses be most helpful to you at this time?
 - Is there anything you would have liked to be in place?
 - Regarding children?

- We have talked about....is there anything else you would like to talk about?
- Maybe something I haven't asked but is really important to you to talk about?
- Do you have any questions for me?
- Thank you for your time and sharing your experience with me.

Family 9: Interview questions - probes & prompts

- Genogram

- Could you tell me what happened last Monday?
 - How did you learn about the incident?
 - Can you remember what you thought/ felt at that moment?
 - How did you learn about the incident, Chloe?
 - Transfer to Edinburgh?

- Is this the first time your family is experiencing a critical illness event?

- How are you coping with the current situation?
 - Free time form Work/ College?

- Where you offered to participate in Phil's care?
 - Would you like to if offered?
 - How do you keep up to date with what is happening/ planned for Phil?
 - Who is informing the extended family of Phil's progress/ situation?

- Who is, from your perspective, the most affected by Phil illness?
 - How does he/she show it?

- What is your greatest concern or challenge at this moment in time?
- Who helps you most with this challenge?

- Summary
- Is there something else you'd like to discuss or raise?
- Questions for me?
- Thank you.

(Note: all names are pseudonyms.)

APPENDIX 6

Examples of support information sheets for adults and young people






Children's & teenager's information resources

Talking about a time when one of your family members was very sick is not always easy. Talking to one another when someone in a family is very sick can help you understand what is happening. However, you may want to access other information resources or would like to talk to someone outside your family for advice or counselling.

The following information aims to help you find advice. You can either phone a helpline or if you have a computer surf their websites.

The symbols are:

 This tells you a phone number  This gives you a web address.  An e-mail address.

Information Resources:


ChildLine


 0800 1111

 www.childline.org.uk

ChildLine is a free and confidential helpline for children and young people with any kind of question or problem.

The National Youth Agency


 0116 285 3700

 youthinformation@nya.org.uk

 www.nya.org.uk

The National Youth Agency is based in Leicester, England. Its website has a lot of information around a variety of themes (for example, family & relationship, health, environment and a lot more) which are of interest to young people.

Parentline Plus

 0808 800 2222 (helpline)

 www.parentlineplus.org.uk

Parentline Plus provides information and support for families. They also have a helpline for parents and carers. As you may know parenting is not always easy! Sometimes parents need some help too. You may even want to check out the website together.

I hope this information is helpful to you.




Susanne

Parent Information Resources

Explaining to children what is happening when someone in a family is critically ill is not an easy task. Sometimes there is a need to access additional information resources or to talk to someone outside your family for advice or counselling.


The following information aims to support you to help your family during a challenging time. The listed information is either accessible by phone or the Internet.

The symbols used are:

 Phone number  Web address.  E-mail address.

General Help lines

Parentline Plus

 0808 800 2222 (helpline)  www.parentlineplus.org.uk

Parentline Plus provides information and support for families. The website provides information for parents and carers as well as for children.

The National Youth Agency

 0116 285 3700  youthinformation@nya.org.uk  www.nya.org.uk

While this website is aiming at young people (based in Leicester, England) it is broad in scope and has a lot of information around a variety of themes (for example, family & relationship, health, environment etc.).



Health Education Board for Scotland (HEBS)

This website provides information and access to key resources here in Scotland.

 0131 536 5500 (General enquiries)  www.hebs.scot.nhs.uk/services/index.htm


Headway - the brain injury association

This is the national website dedicated to provide information and support to families and individuals after a brain injury.

 0808 800 2244 (Helpline)  www.headway.org.uk

There are also local support groups which are listed on the national webpage.

The Dumfries & Galloway group can be contacted under:

 01387 261166
Contact: Sharon Hepburn
Headway House
Afton Drive, Summerhill
Dumfries DG2 9ES

Brain & Spine Helpline

This is a foundation that aims to improve care and treatment and support people with a number of brain and spine disorders.

 0808 800 1000 (Helpline)  www.brainandspine.org.uk

TBI Support Group

This is a website offering general information on a number of head injury issues.

 www.headinjury.com

Spinal cord injury


This is an extensive website offering information about spinal cord injuries in general (i.e. what it is, consequences of a spinal cord injury) but also addresses day to day issues of living with a spinal cord injury (i.e. aids and equipment, friends and dating, holidays and travel, carers and agencies etc.).

 www.spinalcordinjury.co.uk

Head office:


63 Lincoln's Inn Fields

London WC2A 3LW

 020 7242 6462

Spinal Injuries Scotland (SIS)

This is a voluntary organisation that is focusing on new and long-term spinal cord injury people, their families and friends. This organisation is able to give support as well as assistance on a number of issues related to spinal cord injuries.

 0141 314 0056

Spinal Injuries Scotland

Festival Business Park

150 Brand Street

Glasgow G51 1DH

 www.sisonline.org

The listed resources are by no means complete or exhaustive but aim to provide a starting point should you wish to access further information.

Susanne Kean

(Note: This are examples of information resources adapted to families expressed wishes. All information was check on its accuracy prior to handing out.)

APPENDIX 7

Transcript symbols

The interviews were transcribed using some of Silverman's (1993:118) simplified transcription symbols. Transcribing data within this scheme supported interpretation of text since it emphasised the dynamic of interaction. However, to ease reading of presented interview data most symbols were removed.

The reader will however find a small number of symbols within the main text, which were left because they were seen as important not only to understand the dynamic of an ongoing interaction but also in contextualising offered interview data within a group situation.

These symbols are:

- (.5) Numbers in parentheses indicate elapsed time in tenths of a second.
- / Overriding speech
- () Inaudible speech
- (Word) Parenthesised words are possible hearings.
- WORD Capital letters indicate especially loud sounds relative to the surrounding talk.
- Word Underscoring indicates emphasis by participant.
- Hyphen indicates abrupt cut-off by participant.