

AUTONOMY SHOWN IN LIFE HISTORIES OF
ELDERLY PEOPLE AND A NURSING RESPONSE

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Ph.D.
University of Edinburgh
1986



DECLARATION

I declare that this thesis has been written by me and is the result of research which I conducted.

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ACKNOWLEDGEMENTS

I wish to record my thanks to my supervisors, Professor Penny Proffit, Professor Malcolm Johnson and Miss Margaret Clark. Miss Clark gave most generously of her time and insight as well as friendship and good humour despite the fact that her supervision was done on an informal basis. For all this I am grateful. Of Professor Proffit, I find it hard to express the degree and quality of the support which she has given. Without her, autonomy would not have been such an important part of this work. Her quiet conviction that the work would be completed is perhaps her most important contribution.

The personnel of the Institute of Medical Ethics and particularly of the Edinburgh Medical Group have been of great importance. They have provided a milieu in which to develop ideas about ethics and how this vast subject relates not only to life in general but the practice of nursing in particular. I am most grateful to them too for their publications.

To Dr. Alison Tierney, Director of the Research Unit, and my colleagues I would like to record my especial thanks. Joan Anderson and Ian Atkinson particularly have provided much support, both of friendship and stimulating conversation.

A trio of patient women, Mrs. Lynne Dyer, Mrs. Elizabeth Glass and Mrs. Kay Rich, have reduced much untidy script to its present form and to each of them I am grateful.

I would not want to let this opportunity pass without acknowledging the influence of my immediate family. Without their stimulus individually the work would not have been done.

Lastly the respondents who I cannot thank sufficiently for their involvement, their willingness, their openness, their kindness and their time. I greatly enjoyed them severally and together and they will remain with me always. Their experiences will, I hope, affect future practice and I trust that they will accept that as reward enough.

ABSTRACT

The objectives of this study were: (1) to conduct a theoretical analysis of autonomy; (2) to seek operational manifestations of autonomy in life histories of a sample of elderly people; (3) to find examples of choice relating to their experience of health care; and (4) to suggest ways in which nurses can nurture and promote autonomy in elderly people.

The first part of the review of literature concerns various ideas surrounding the concept of autonomy. An extensive analysis of this review, as well as related concepts like freedom and paternalism, lead to the conclusion that there are three dimensions: autonomy of thought; autonomy of will; and autonomy of action. A model was devised showing the hierarchical and functional relationship of these dimensions. This model was used as the framework for the analysis of the data.

Because the patient group studied was the elderly, attention was given in the review to theories of ageing as well as various facets of autonomy and the elderly. The philosophical focus was continued in an examination of the moral bases on which health care in general and nursing care in particular are carried out.

The operation of autonomy was demonstrated in a group of 13 people, of both sexes, aged 70 years of age or more. The members of the group had all had recent experience of being in

hospital, though not in connection with a psychiatric illness. They were all living in the community. The method used to elicit the information was a topical life history, which focused on how decisions had been made during their lives. These data are presented in two sections. In the first, the life histories are set out and, in the second, facets of the decision-making process were isolated and discussed.

The importance of autonomy to the understanding and practice of nursing is discussed. The means by which nurses can nurture and promote autonomy completes the final discussion section. Conclusions concerning autonomy of thought, will and action, and recommendations are proposed for the areas of education, management and further study.

CHAPTER 1

Introduction

CONTEXT AND BACKGROUND OF STUDY

The stimulus for this study came from work undertaken in the Nursing Research Unit as part of the core programme of research funded by the Chief Scientist Office of the Scottish Home and Health Department. The 1970s saw a rise in the numbers of elderly people for whom the National Health Service took some responsibility (DHSS, 1980), and an increasing interest in studying problems of the elderly. Growing awareness of the special needs of the elderly, development of research projects, and increased provision of services to meet the rising demand give evidence of this interest. The erection of purpose-built units which were intended to facilitate better practice by members of both the medical and nursing professions, as well as create a more suitable environment for the residents shows a similar pattern. As many of the elderly require long-term nursing care, as distinct from treatment of signs and symptoms of acute illness, it seems appropriate that nurses contribute to the search for the best help and care for elderly people.

In 1978 the Nursing Research Unit developed a core programme of research focused upon communication in a variety of settings and modes. In effect the core programme was a series of studies within this central theme and, in one of these studies, Melia and Macmillan (1983) examined some of the problems of communication related to elderly patients when they moved between the community and hospital as a result of acute episodes of illness. In pursuit of this work the author had responsibility for the collection and interpretation of data

about the information collected from and about elderly patients when they went into hospital, and the handling of similar information when these patients returned to the community. These data were obtained from trained nurses in the hospital setting. The data showed quite clearly that there were difficulties of communication between the community and hospital nurses, and, perhaps most perplexing, that the patients were the silent partners in the decision-making process (Melia and Macmillan, 1983). In other words, the professionals were making decisions with little more than tacit reference to the patients, and only after the decision had been made were the patients involved in the implementation of these decisions. Though explanations can be posited for such a situation, it was felt by the author that this apparent lack of consideration of the patients' view was unnecessary and indeed improper in many instances. Such a state of affairs provoked thought about how some decisions are made in respect of the elderly, and the present work was seen as a possible, and indeed useful, outcome of the previous study. In general terms, one element in how decisions are made rests upon the autonomy of the individual patient in collaboration with the professionals making the decision, and it is upon this area that the present study focuses.

Though it would be possible to carry out work which would be of relevance to a restricted population, nursing research still requires to answer difficulties of a wider community. The label "elderly" covers a large and indeed growing section of

the population. From the data collected during the Scottish part of the 1981 census it is clear that until 1991 the numbers of retired people will grow from 867,000 (representing 16.8% of the total population) to 878,000 (17.3% of the total population). Although thereafter there will be a small decrease by 2001, when the estimated figure will be 861,000, the percentage will not have fallen much at all. The important demographic change, however, will be a rise from 273,000 to 321,000 in those aged 75 and over (DHSS, 1985). Various Government documents published around 1980 very clearly pointed out the trend of overall increasing numbers of the elderly, but also underlined the increasing numbers of the very elderly and made suggestions for changes in priorities and patterns of care (SHHD, 1979; 1980a; 1980b).

Bauchier and Williamson (1982) comment that this factor of ageing alone would lead us to acknowledge that the numbers of elderly people who will come under the care of the health services, which of course include both hospital and community, will increase. It means inevitably that a variety of options of care must be made available to provide appropriate services (SHHD, 1979; 1980). There are implications also for those who care for this age group. Charlesworth et al (1984) have analysed data on 'carers' (i.e. families and/or friends) and drawn rather bleak conclusions about the realities of looking after relatives, neighbours or friends in the community in the era of increasing shortage of facilities and professional help.

That relationships between patients and hospital staff are fraught with difficulty has been spoken of by many researchers. Robb (1967) gives a most depressing picture of elderly people having teeth and hearing aids removed, and being kept in bed unnecessarily. The whole picture of the unpopular patient and how nurses attempt to control such people has been eloquently described by Stockwell (1972). Evidence is reported by Raphael and Mandevill (1979) that only patients who can dress themselves have any control over the decision of when to get up or go to bed. They also write of elderly patients being kept in bed all day on a regular basis as a response to staff shortages. Rosenthal et al (1980) found that the provision of information by patients was limited to that deemed relevant by nurses, and also that the professionals decided and controlled patients' activities. Tinker (1981) cites evidence that the dignity of patients is not always preserved, and independence and mobility are not always encouraged. Nurses in acute wards revealed that they would prefer not to look after physically handicapped patients (Atkinson, 1984). Patients also experience difficulties with the settings in which 'care' is carried out. This does not augur well for the decisions which will inevitably need to be made by many people for themselves, or by relatives and professional carers, when help is sought for elderly people from the health service and other caring agencies.

As with much research, the purpose of this study is not wholly altruistic. With one's own increasing years, the

inevitability of being old, or one's parents becoming old, perhaps increases the sensitivity and awareness to the problems which may well have to be faced. For one who is in the habit of making decisions for and about oneself which seem proper at the time, the prospect of no longer being able to exercise that ability or having it hampered by impairment or social convention is one of the most daunting prospects an individual faces. If this work can help enhance or even merely preserve such an attribute for as long as possible, then for others and perhaps oneself it will have been worthwhile.

The difficulties of not having one's decisions taken into account are enunciated by Newton (1980). She kept a diary as she was moved from a nursing home to other similar institutions. She tells graphically of the difficulties of being looked after by some members of staff who carried out their duties professionally and others who did not, in rather dreary surroundings where her views, questions and sometimes even simple requests were not listened to. For the sake of her family, she and they went on pretending to each other that all was well until, after six years in such a plight, she managed eventually to persuade everyone that the right place for her to be was at home, with all the possible risks involved. Six years is a long period during one's seventies to have to struggle to achieve what is right for one. Such a struggle is not unique and, sadly, it may be that very many are never able to achieve their goal.

THE DEVELOPMENT OF AWARENESS OF ETHICAL ISSUES AMONGST NURSES

Philosophy has been the discipline which has contributed the study of ideas to the world. The particular branch of philosophy which refers to behaviour and good and evil is moral philosophy or ethics. It is within the scope of ethics that the discussion of values and principles is to be found. The present work has been based on three principles, in which it is suggested care of people can be carried out, namely: justice; beneficence; and respect for persons. These three principles share autonomy or self-determination as a common basis. The fairness of giving care due to an individual is intimately related to what that individual decides is proper for him. Having a duty to care for others equally depends on one deciding that he needs care and the carer responding appropriately. The treating of people as people can only be achieved if there is an accompanying commitment to allow individuals to make decisions for and about themselves - decisions which are taken seriously by others. Numerous moral philosophers have written about the concept of autonomy and therefore it was the ideas which these authors developed upon which the work was founded.

Ethics was a subject not much addressed in nurse curricula of two or so decades ago. Etiquette or morals, however, were considered important topics, but thought largely to have been learned before nurse preparation began. The last twenty years, however, have been an era of public debate about difficult ethical choices of such issues as abortion, organ transplant,

resuscitation and intensive therapy, among many others. Circumstances as well as inclination stimulated a personal interest in the principles which underpin such decisions. Involvement in ethics courses and participation in groups where medical ethics have been discussed on a multi-professional basis have provided the opportunity to extend knowledge in this field. Such links have also given the chance to identify and examine the principles which individuals use when making personal decisions about ethical issues.

As ethical issues related to clinical practice have become more complicated and widely debated, nurses have needed to be active in the debate. They, as practitioners in a discrete health discipline and as members of society, cannot always accept that a physician's ethical decision and subsequent action necessarily conform to their own view, either in terms of their own stance or that of the patient. Such complexity can be seen in the example of a general practitioner who has come to a decision that a mentally handicapped unmarried girl should have a termination of pregnancy following amniocentesis, when, on the other hand, the health visitor attached to the practice may think that the girl's needs would be better served if the pregnancy continued to term. The health visitor may hold the general view that termination is only proper if the life of the mother is in jeopardy. Here, then, we have two professionals and two patients, the mother and the unborn child. The professionals each have personal moral stances which are different from each other and each have come to ethical

decisions about two patients. Both patients, for different reasons, have difficulty in taking part in the dialogue as to what is 'right' for them. Various strategies could be suggested as to how these equally well-intentioned professionals came to the 'right' decision for this mother and her unborn child. MacIntyre (1983) suggests that the divide of doctors curing while nurses care, as is suggested in the case above, is not satisfactory. His response is to suggest that nurses should be "interpreters or translators" between doctors and patients, but also that the process must ensure that doctors understand what patients say, understand and decide. Such an ability, he claims, could not be carried out without sensitivity to individual patients and some degree of preparation in philosophical discourse.

Many nurses, considering that all was not well with their practice, have attempted to improve things, at least in part, by implementing the nursing process (Yura and Walsh, 1978; Hunt and Marks-Maran, 1980). In essence, nursing process attempts to carry out nursing care in a systematic, thoughtful, individualised manner and to focus on issues beyond those which are obvious and physical. One of the fundamental elements in the problem-solving process is to draw up, where appropriate, the patient profile which is a word picture of the patient, his background, social setting and daily habits which gives a basis for clinical judgement when nursing action is being suggested, carried out, and its effectiveness assessed. This process would seem a ready medium in which to practice the art of "translator". An argument, however, can be made that a gap

remains in that the autonomy of the patient, whatever his age, is somehow missing in the patient profile in that the focus is on 'what is' rather than on 'how it came to be'. Another argument that could be suggested as to the nature of the gap is that it has not been properly explored and that it centres around thinking rather than action. The question of whether that patient had a choice and, if so, how or why a particular choice was made is not enunciated. Though this need to make decisions is there for any patient, the area of decision-making becomes even more significant in the case of the elderly since that age group may be less able to demand choice. Gaining such knowledge about a particular patient might enhance the desire to care for that patient as an individual.

Inherent in the appropriate care of others is the principle of respect for persons. One of the attributes which is most fundamental to our considering people as persons is recognition of their ability to reason (Aristotle, 1953). The activity of 'making up one's mind' or choosing to follow a particular course of action is a demonstration of that ability.

The requirement to work out an appropriate course of action with an individual is called upon frequently in relationships between patients, and doctors and nurses. For example, when consent is sought from a patient to carry out some procedure, the reasoning ability of both patient and carer is called upon when the patient has implicitly to make up his mind as to what is right for him. The patient can be said to be autonomous if he is able to say, "Yes, I realise that if I do

not accept immediate treatment for my broken hip then I will jeopardise my life. But in spite of that knowledge I refuse permission for you to instigate any treatment". On the other hand, he can be as autonomous if he accepts the treatment as it is suggested to him.

The exercise of such a right to refuse treatment may be difficult to accept but that does not allow the carer to deny it or, even worse, not to realise that such a right exists. The concept of autonomy is one which is most easily challenged at the edges of life (the very young or the very old) and where rationality is in question. It becomes easier to dispense with its consideration when the patient is unborn, a child, or unconscious. Consideration of autonomy becomes contentious when the patient is mentally handicapped, mentally ill or very old (Childress, 1982; Culver and Gert, 1982). There are then categories where it is easy to dispense with consideration of autonomy; others where it can be argued about; and yet others, such as the young fit adult, where there should be no debate about not giving autonomy free rein. But even here the health professions need to be encouraged to recognise, guard and enhance autonomy. It will be argued, however, that the edges of life and rationality should be extended as widely as possible. Age alone should not be an issue. It is rather the individual's ability to be making decisions about himself which should be the criterion by which professional carers make their interventions and recommendations. Since professional carers have by definition more knowledge in some areas and sometimes

more experience, this knowledge needs to be shared with patients so that whatever decision is reached it is an informed and thoughtful one. Such decisions, whether they be what the individual nurse would decide for herself or not, have a greater moral weight to be defended and acceded to if they have been reached by the patient on the basis of knowledge.

USE OF A LIFE HISTORY METHOD TO STUDY AUTONOMY

The concept of autonomy is not universally agreed in all its nuances nor, indeed, in how to facilitate its practice, but one of the elements which is much spoken of in any discussion of the concept is that an ability to reason must exist. Reasoning ability is notoriously difficult to measure and any attempt to isolate a particular aspect of this ability is even more difficult. This is shown in the debate about IQ testing which has gone on for many years (Gould, 1981; Jensen, 1981). But before measurement is possible one must agree components with which to start such a process.

Even if a definition were stated and agreed the problem of finding examples of it in a variety of people would remain. When faced with such a situation one requires to proceed with a method which allows for what might be called "constrained intuition", that is to say the acceptance that 'truth' can be perceived by means which are not amenable to reasoning and analysis in the conventional logical sense. Such intuition, however, cannot be allowed to rush headlong along a diversity of routes; rather it needs to be bridled or constrained until

the intuition can be elucidated, checked, confirmed or merely enumerated by analysis and reasoning. Therefore a qualitative method had to be sought to conduct this study.

When attempting to describe the operation of a concept which has no fixed definition in a group of people such as the elderly, an historical approach was deemed to be the most appropriate one to elicit the information. Patterns over time have more substance than single events and such patterns are indeed only revealed in the repetition. Blyth (1979) demonstrated that patterns do emerge from interviews with elderly people about their lives. The decisions elderly people have made during their lives must be a major component in the explanation of their present lives.

It is a truism to say that people love to talk about themselves. Old people have much which is fascinating and important in their memories and it is a pleasure as well as a privilege to be the one who can persuade people to share these stories through the encouragement of reminiscences. Many of us find it difficult to talk about or explain why we think or do as we do and frequently resort to illustrations to advance argument or amplify our views. Sometimes we only see a pattern after several illustrations have been cited. If MacIntyre (1983) is right that nurses need to be "translators", the activity of listening with sensitivity and imagination to the life histories of old people, redolent as they are with the past and its effects, seems to be a good place to begin.

THE OBJECTIVES OF THE STUDY

On the basis of this background, the following objectives were formulated:

1. To analyse autonomy theoretically.
2. To discover operational manifestations of autonomy in life histories of a sample of elderly people.
3. To ascertain whether examples of autonomous choice directly relating to health care were present in the life histories of a sample of elderly people.
4. To suggest ways in which nurses can nurture and promote autonomy in elderly patients.

THE LIMITATIONS OF THE STUDY

The study was carried out with the help of 14 elderly people who were aged 70 years and over. They were resident in the community, though they had been in hospital for an acute episode of illness within the previous year. None of the group had a history of psychiatric illness. The group was nominated by parish ministers. All these factors, though making them suitable for inclusion in the study, do mean that they are not completely representative of the elderly population. As the purpose of the study was to describe operational manifestations of autonomy, no statistical analysis was made of any influences of a sociological or cultural nature on an individual's ability to be autonomous, though these were recognised.

Other possible respondents such as those in long-term care, those who suffer speech problems, profound hearing

difficulties, or those who experience psychiatric illness have much of relevance to contribute to the debate of autonomy. But that is a possible further development of the present work.

THE ASSUMPTIONS OF THE STUDY

This study was carried out in the community on the assumption that the respondents would be better able to think about a difficult concept because they would be secure in their home setting and would also have more time without interruption in which to enter into the exercise. It was also assumed that they would tell the truth as they perceived it in relating the incidents that have made their life stories. The fact that they had each had recent hospital experience would make it more likely that they would be able to enter into debate, or at least have views, about the influence of autonomy and their care and carers.

THE JUSTIFICATION FOR UNDERTAKING THE STUDY

Autonomy has largely to do with individual people making decisions for and about themselves. It follows, since it is a matter for individuals, that people are entitled to express what is right for them and, more importantly, to be assured that their wishes will be respected. Such entitlement and respect do not always follow. There can be difficulties for the group labelled as 'old' which arise from a societal view that making decisions is an activity which the old can no longer

manage, and indeed one in which they ought not to be involved. For some people it is impossible because of their condition, as in extreme cases of dementia or unconsciousness. There are others whose autonomy is not heard nor acceded to because carers, either formal or informal, are seemingly unaware of the need.

Cloke (1985) indicates from research on carers of elderly people that such people are aware of the problems experienced by the elderly and know what solutions the carers, and the elderly whom they care for, would wish to select. Those sampled in Cloke's work are, for example, aware that some elderly people need almost constant attention over the 24 hours or a varied selection of services which would require to operate each day of the week rather than on a Monday-to-Friday basis. When these solutions are put alongside the wish of the elderly to stay in the community breakdown happens. Carers who ignore the choices made by those they care for may not be malicious but merely ill-educated or over-worked since to discuss the ramifications of a particular decision might be a lengthy process, and may indeed be at odds with what the carer believes to be right, or what he knows he can provide.

Very many decisions, particularly in the health care field, are made for people without their active involvement. Explanations such as control of patients (Friedson, 1970); maintenance of superiority of knowledge (Kennedy, 1981); practising paternalism (Gert and Culver, 1979); the rise of professions (Illich, 1977); lack of time to talk to patients

(Melia and Macmillan, 1983); and patients being wary of nurses (Hardie and Macmillan, 1980; Melia and Macmillan, 1983) have all been used as excuses for unilateral decision-making by health care workers.

A lack of patient involvement in making decisions for whatever reason has several possible outcomes. The patient may merely acquiesce meekly and be pushed further into a state of limbo. Inappropriate decisions may be made for individuals which, once made, may prove impossible to retrieve or change. Increasing disenchantment with health care and with the individual's lot is another possible outcome, despite an acceptance that the 'right' decision was reached. For the sake of humanity in health care all these possibilities require to be diminished or prevented.

Nurses are a major group within the health care system and indeed are unique in their ability to offer 24-hour care to any patient, as well as being fundamentally involved in the care of the elderly. Nurses are therefore in a position to make a unique contribution by improving the quality of the care they offer rather than leaving change to be imposed from outwith nursing. Indeed failure to take some initiative in this area might beg questions for further study, namely the autonomy of nurses as independent practitioners working within a multidisciplinary team. Such changes would, in turn, improve the quality of life for individual patients. By awareness of autonomy, and cherishing and encouraging its practice, these ends would be achieved. One way to start change within nursing

is by recognising, and so adopting in practice, the respect for the individual person which necessitates knowing him and thus prevents inappropriate categorisation with all its ramifications.

THE SIGNIFICANCE OF THE STUDY

It has largely been philosophers who have addressed and written about the concept of autonomy. Those in the fields of social work and social administration have also addressed the question of autonomy with particular reference to responsibility towards clients and risk taking. Recently those, often with a philosophical or theological background, who are specially interested in medical ethics have taken up ideas related to autonomy like paternalism. Very many of those who have written in the field of medical and nursing ethics have been American and though they have many insights to share with the British system where theoretical and philosophical bases are shared, there are aspects, such as attitudes, inter- and intra-professional relationships and the cultural milieu, as well as the National Health Service itself, in Britain which are different. It is appropriate that someone who has a knowledge of the field of ethics as well as having worked as a nurse within the system should write about autonomy.

Sadly, there are many elderly people who are in-patients in hospitals but are, for varying periods of time, inappropriately placed. For example, it is possible that a patient may be in a medical ward awaiting transfer to an

assessment unit, and then in the assessment unit for many months awaiting a place in 'Part 4 accommodation', which refers to the section in the 1968 Social Work, Scotland, Act that undertakes to provide accommodation for those who can wash, feed and dress themselves as well as being able to walk up and down stairs unaided while requiring some extra care. During this waiting period, the aims of the care given to the patient should be much involved with maintaining and enhancing the independence which will be needed to be able to live successfully in the community. These aims are very likely, however, to be submerged in the requirements of a large amorphous institution which encourages dependence. Research which draws the attention of managers, practitioners and teachers of nursing to the needs of individual patients should help care to be more adaptable to the eccentricities of isolated cases when they occur, as well as the usual uniqueness of any patient.

Acceptance that a holistic approach in nursing is a right one is gaining credence, but how that approach can and should be implemented in practice continues to be a problem. This study is significant because it has concentrated on what patients have said and perceived rather than on nurses' assumptions and inferences based on limited evidence. From patients, techniques or signposts can be learned which will help in the care of other patients or clients in the community.

Although for many practising nurses education in philosophical reflection has been lacking, there is an

increasing awareness that this gap exists and needs to be filled. Such a study as this has a contribution to make in demonstrating that seemingly abstract ideas have very practical outcomes for the benefit of individual patients and for good nursing practice. By pursuing a concept such as autonomy which has considerable practical significance for the benefit of all patients, the elderly in particular, nurses may readily be assisted to understand the relationship between abstract notions and the daily practice of their work.

One of the daily tasks in which nurses are involved is the writing of patient profiles in the implementation of the nursing process. This study makes a contribution by drawing attention to a significant gap in the patient profile. Not only does it make the gap clear but goes some way to identifying what is required to fill it in terms of considering and noting how patients think and make decisions. By ascertaining and honouring the decisions made, nurses may not only give patients better care in the fullest sense, but also find their work more satisfying in doing so.

This study has the potential to contribute to the understanding of the concept of autonomy by the development of a framework which could be used to analyse the operational manifestations of autonomy. Ultimately, this framework could help nurses to continue the search for a more complete understanding of the nature of nursing. A framework that could be used to analyse manifestations of autonomy could also assist health care professionals to understand the difficulties which

a particularly vulnerable group, the elderly, have in exercising choice in their care as well as in their lives. The promotion of self-care and the enhancement of autonomy are fundamental to the nature of nursing and to the development of nursing theory which guides nursing practice.

CHAPTER 2

Review of Literature

OVERVIEW

The review is organised into three sections. The first concerns what philosophers have said about autonomy and the factors which affect it. The moral justification for providing health care and the necessity for nurses to be conversant with theories and philosophical concepts is noted. The second section considers the ageing process and the various explanations which have been offered to help understand it. Some historical background is also included which shows attitudes towards the elderly and their care. In the third section autonomy and the elderly is examined in relation to factors which profoundly affect this group and their exercise of self-determination.

The literature in this review covers a long period. Philosophical writing provided the basis for the study but the work of theologians, ethicists, psychologists, anthropologists and sociologists as well as diarists, novelists and poets have all been included in the review. Some nursing references have been cited in this section though the main nursing contribution appears in Chapter 6. Research figures mainly in the section on ageing and in the last concerned with autonomy and the elderly. In the nature of things there is a dearth of research in the philosophical section, which results in the works being essays, philosophical treatises or journal articles.

At the end of the literature review there is a section which explains the author's model of autonomy developed from analysis of the literature with the relationship among the

dimensions of the model. This framework was used to analyse the life history data.

AUTONOMY

INTRODUCTION

In defining autonomy many writers down the ages have taken the idea of self-determination and, as if it were an onion, have peeled away many layers such as free will, goodness, causality, rationality and liberty in an attempt to reach the core. At the same time, they have put increasing importance on the "onion" as a whole in terms of rights. How all these ideas fit into the health care field is one of some difficulty since illness, age or handicap, either physical or mental, will seriously affect at least some of the "skins" if not the "onion core" itself. The other difficulty in the complexity of health care is about rights and how they can be acceded to or implemented.

SELF-DETERMINATION

What Self-Determination Means

In the public mind autonomy means the power of self-government or self-determination; it is, in other words, all about choice. By their choices it may be assumed that people who have achieved adulthood have exercised autonomy. They have made a great many decisions for themselves, both great and small; choices such as "What job will I do?", "Will I marry?", "Will I leave home?" or "How will I spend my money?"

and, on a smaller scale, "What will I wear?", "What will I eat?", "Which book will I read?" or "How will I spend this evening?". These choices can be said to exhibit self-determination, or autonomy. Such choices not only show self-determination but also pre-suppose freedom.

Mary Warnock, in her paper 'The Nature of Choice' (1983), has pointed out that philosophers from time immemorial have asked questions about human choice. According to Aristotle (1953), choice is a deliberative stretching out towards something that it is within one's power to have or to do. He is saying, in effect, that one does not deliberate about, and therefore does not choose, things which are completely outwith one's control. Such an activity would be day-dreaming or something of that order. There is a consistent reference to deliberation and subsequent action, but with the necessary component of the ability or power to achieve one's ends. Kant (1949) also makes clear that autonomy is based on rationality. As has already been suggested, human thought and inherent free will are the foundation of autonomy, but it is not complete without the freedom to act upon or carry out the deliberative choice. There are those who think that people who cannot deliberate are without autonomy. Hume's (1902) view was that when we talk about free choice we mean that we act as we wished or willed to act. We feel that there is reality in our having made choices and that there were constraints if we did not do what we wanted to do. This would indicate that reason helps us to decide how to act.

The converse of these ideas has been described as "heteronomy" by Kant (1949); that is to say, being ruled by other people or outside conditions. Clearly actions which are committed by coercion are heteronomous but Kant also included in heteronomy, actions arising from impulse, habit and desire. Someone who acts out of desire eats a fifth chocolate biscuit rather than eating an apple, which would better promote health and show choice by reason. Such a choice could not be autonomous since the "will" has been subjected to a motive or rule outside itself.

As a means of trying to draw together all these strands of what self-determination is about, Miller's (1981) exposition of autonomy might be helpful. He wrote:

"At the first level of analysis it is enough to say that autonomy is self-determination, that the right to autonomy is the right to make one's own choices, and that respect for autonomy is the obligation not to interfere with the choice of another and to treat another as being capable of choosing. This is helpful but the concept has more than one meaning. There are at least four senses of the concept as it is used in medical ethics: autonomy as free action, autonomy as authenticity, autonomy as effective deliberation, and autonomy as moral reflection". (p.24)

Miller goes on to explain what he means by these four aspects of autonomy. Firstly, by "autonomy as free action" he means that it is a free action made without coercion or undue influence. A person may accept treatment or refuse it, but if the doctor carries out a procedure on an unconscious patient then that would be an example of autonomy as free action on the

part of the doctor but not the patient. Secondly, "autonomy as authenticity" refers to an action that is consistent with that person's known beliefs or attitudes. For the action not to be authentic it would have to be "unusual or unexpected, relatively important in itself or its consequences, and have not apparent or proffered explanation". Obvious difficulties arise if one believes that individuals from time to time do radically alter their beliefs. Thirdly, "autonomy as effective deliberation" means action by someone in a position which calls for a decision after taking into account the possible alternatives and their consequences. This would be the basis, for example, of informed consent. Fourthly, "autonomy as moral reflection" indicates that one accepts the moral values on which one acts. Obviously to have achieved such a degree of self-awareness and acceptance of values or beliefs after looking at the alternatives is no easy task and cannot possibly be carried out quickly or easily.

How Self-Determination Works

1. Causality:

Much of the philosophers' interest in self-determination has centred on free will. The question, "Are we free agents?", is a curiously deceptive one. A quick reply of "yes" or "no" demands qualification. Of course there are some acts which are plainly involuntary like sneezing, breathing, or the knee-jerk reflex, while there are other acts which seem to be consciously controlled, such as walking across the room, playing the piano, or writing words on a page. Most people feel that they do make

choices about things and yet there is the feeling that there are also external causes for things (Bishop, 1983; Stalley, 1977). Indeed most painful experiences, like a sudden death, are more tolerable if it is known why they happened. Perhaps there is need to differentiate between happenings such as heartbeats, earthquakes, or trees being blown down and actions like signing cheques, driving a car, or choosing to eat a cream cake. In the first set of happenings there is no human volition involved, while in those of the second sort there is a human agent who is the instigator of the action. Of the first sort of happening some would say that such things were acts of God (O'Conner, 1972) but this still leaves other explanations of why things happen. Kneale (1949) described the causal effect as the "necessary corrections". On the other hand, Popper (1972) argues that it is consciousness which is the explanation of why things happen.

2. Laws of Nature:

Descartes (1970) had a mechanistic view of physical events, in the sense that each one was the effect of a previous one and would in turn be the cause of further events. The relationships between physical events were seen to be governed totally by the laws of nature. These laws were ordained by God and were therefore immutable. The ideas of 'laws' governing nature can be exemplified by the coming of spring with warmth, light and rain, and so because of these events the daffodil bulb shoots leaves and buds. It would be extremely confusing if all this happened in the depths of winter. If it did claims

would be made that natural law had been breached. Descartes further held that people only had to discover the laws of nature rather than attempt to find out God's purposes. By understanding the laws they could then make accurate predictions about what would happen. This means that all events are determined since everything that happens must happen inevitably; there is a pre-ordained divine plan.

The fact that human beings are physical means that they too are pre-determined. Such a belief is the essence of determinism. Leibniz (1954) held that the fate of individuals as well as the natural world was predestined. St. Augustine and Calvin are perhaps the most famous exponents of the doctrine of predestination. If God has predestined what man will do, then free will is an illusion. This view has been modified by various thinkers. Milton, for example, in 'Paradise Lost' (1980), makes a clear distinction between predestination in the sense that God had ordered the fall and, on the other hand, that He had made man with an ability to choose but His omniscience allowed knowledge of the fall while allowing that choice to be made. This does little or nothing to help with the difficulty of whether or not we have free will.

3. Free Will:

Those who do claim free will may subscribe to libertarianism (Campbell, 1967). This view holds that human actions are not entirely physically determined. The thoughts, desires and intentions which lead to actions are not clearly the result of previous events over which the individual has no

control. They claim that one is free on a given occasion if it is possible to choose differently, even providing all the circumstances are the same. Hume (1902), while not refuting the idea that there are causal relations, said:

"When it is asked 'What is the nature of all our reasonings concerning matters of fact?' the proper answer seems to be, that they ponder on the relation of cause and effect. When again it is asked 'What is the foundation of all reasonings and conclusions concerning that relation?' it may be replied in one word 'Experience'".

(p.32)

Though we are accustomed to observing the results of actions and their processes which leads to the view that events are caused, this does not mean that there is an inevitable logical connection.

Although there are opposing views about free will and freedom, neither seems to be able to persuade the other that one is right. Even after rehearsing both sets of arguments drawn from a huge literature, there are writers such as O'Conner (1972) and Trusted (1984) who are prepared to state that neither determinism nor libertarianism have an overwhelming claim for adherence and each suggest that there must be toleration of ambiguity. And indeed there are those such as Lamont (1981) who claim that the ambiguity lies not so much with determinism or libertarianism but with the nature of choice, so that where a moral issue is being argued rather than a simple choice then in that case the notion of causality is quite inappropriate.

If there is no clear view to be followed as to whether free will is a reality or not there still is an innate feeling

that in fact decisions are made, and indeed the present writer would claim that free will is a distinct possibility and for this reason has chosen to pursue the matter of choice. The choices that have to be considered include at least some that are moral choices, that is to say whether or not it is right to do things.

FACTORS WHICH AFFECT CHOICE

Various writers have cited a variety of factors which affect the choices we make, and indeed raise the fundamental question of who can make choices at all.

Capability

The idea of 'capability' is a difficult one since it raises the question of who should or cannot enjoy full autonomy. Mill (1974), amongst others, adds caveats about maturity when writing about choice. He writes, for example, that:

"... it is perhaps hardly necessary to say that this doctrine is meant to apply only to human beings in the maturity of their faculties". (p.69)

One difficulty which makes maturity a hard notion to get hold of, however, is that it varies over time and indeed within situations. Maturity can be the explanation for lack of physical strength, both in the sense of not having achieved it yet in the young and in an increased degree of maturity which, in some cases, means a diminution of physical strength from a past peak. A similar point can be made about mental maturity, though there are some who see maturity in the mental sense as

being properly developmental. Therefore the facet of making choices can be seen in the same vein as has been suggested in the work of Kohlberg (Diesen, 1978). If defining maturity is difficult the problems of defining capability are worse since it can affect autonomy, both of will and of action equally, in those who have been accepted as being mature.

Character

Character is another factor which has been associated with autonomy. Aristotle (1953), while examining choice, made clear that he understood goodness as a matter of having a particular sort of character, which in turn determined choice. Certainly this is an idea which still makes sense to the present-day man. People are described, often after they are dead, as having been good and from that perception it can be expected that good actions have followed. One's character should give a certain integrity or consistency to the choices made; for example, brave men make brave choices. Benson (1983) developed this idea by moving from character to characterisation which shows itself by relying on personal powers of choosing, forming opinions and acting. O'Neill (1984) underlines the reality that individuals possess what she sees as a characteristic in different degrees.

The Moral Community

An integral part of moral choice must be responsibility and therefore free will must be active in the process since there is a possibility to choose differently all circumstances being equal. For example, to claim to choose to drive recklessly is to be prepared to accept the responsibility

inherent in the act of driving, but it remains that the choice to drive at a proper speed is a real one. The traditional idea of culpability suggests a duty outwith any causal process to choose the 'right'. In Scots law:

"Culpability consists in conduct lacking in reasonable care, in doing or omitting to do something which in all other circumstances of the case, would not have been done or omitted by a prudent and reasonable man".

(Lamont, 1981, p.80)

The prudent or reasonable man is one who belongs to the moral community. The concept of the moral community, according to Neville (1978, p.34), "is an ideal that exists in pure form only in the imagination". Membership of the moral community is exemplified by individuals being responsible morally for their actions and such responsibility being accepted by the total group. Obviously children, for example, are not seen as being totally responsible. Rather it is a slowly achieved status. That status is achieved by increasing capacity, which is a matter of maturity and experience, but also learning what is acceptable to a wider audience than the individual and his immediate family. The total community, then, has a responsibility to help with the achievement of capacity to interpret the laws and constrictions within which behaviour is measured.

Principles

Our decisions are affected not only by rationality and character, but also by the influences of what the moral community has assured us are important factors against which to judge what we will do. These factors have been unified and can

be stated reasonably succinctly as principles against which views or judgements can be examined.

(a) Universalizability:

Kant (1949) claims that this activity of decision making is based on moral principles which, while personally derived, are governed by the maxim of universalizability. This maxim states:

"There is, therefore, only one categorical imperative. It is: Act only according to that maxim by which you can at the same time will that it should become a universal law". (p.80)

G.J. Warnock (1964), in his discussion of Kant's philosophy of morals, says that:

"... what that imperative requires is that it demands of a rational being consistency of judgement: the rules by which his own conduct is determined cannot by him be arbitrarily restricted from application to the conduct of others also". (p.308)

(b) Ends not means:

Kant (1949) further argues that his essential point can also be stated in the formula that "man and in general every rational being exists as an end in himself". If one uses another individual as a 'means' (for example, by not giving him sufficient information to make a decision which might be opposed to what a researcher would like), then one ignores that individual's ability to be an independent and rational judge of his actions. The obverse would be to treat the individual as an "end in himself" and so accord to him the same opportunity to make decisions as one claims for oneself.

The Influence of Public Opinion

Another area to which Mill (1974) drew attention, and which has acquired weight almost equal to a moral principle, are the bounds which society allows us to operate within. Mill was interested not only in the power of governments but also in the "moral coercion of public opinion". His solution to the problem was:

"... one very simple principle ... That the only purpose for which power can be rightfully exercised over any member of a civilized community against his will is to prevent harm to others". (p.39)

He thought that conformity to established patterns reduced individual productivity and creativity. If individuals worked at enhancing their ability to make judgements, then society as a whole would benefit, a view still being aired one hundred years later.

When considering liberty, Mill said that consideration had to be seen from two aspects. Firstly, the inward man, where there is an absolute right to "freedom of opinion and sentiment on all subjects". Secondly, the public man, where there is an absolute right of "doing as we like, subject to such consequences as may follow". These "consequences" are the "inconveniences which are strictly inseparable from the unfavourable judgement of others". Day (1964) points out that Mill thinks that restraints on liberty of action tend to have adverse results on the individual's interests. He continues that the:

"... reason is that although it is an important truth that men are in general the best judges of their own interests it is by no means true that they are the best judges of the interests of others". (p.360)

These two views then of "autonomy of will" and "autonomy of action" are clearly complementary. Individuals act by what Komrad (1953) calls the "a priori universal laws and also a liberty to pursue self-regarded actions in so far as they do not harm others". Beauchamp and Childress (1983) elaborate on these ideas in their definition of the autonomous person as being one:

"... who deliberates about and chooses plans and is capable of acting on the basis of such deliberations, just as a truly independent government is capable of controlling its territories and policies".
(pp.59-60)

Unrecognised Influences

Though it is so that decisions can be based on universal laws and with consideration of their effects on other people, it remains that there are outside influences which can be overwhelming, perhaps the more so because we are not fully conscious of them. As an aside, Warnock (1964) interestingly points out that although Kant insists:

"... that the moral law is autonomous self-sufficient, and in particular independent of religious belief, the moral outlook which he expands is clearly that of the somewhat rigorous Christian sect in which he grew up". (p.308)

Our ideas, in other words (though we might find it convenient to deny it or merely be unaware of it), are drawn from a history of thought involving not only the Greeks, but

also the Judaeo-Christian tradition and later thinkers as well as immediate and personal influences. Tillich (1981) drew attention to this when he wrote while defining autonomy as:

"... obedience of the individual to the law of reason which he finds in himself as a rational being. Autonomous reason, in affirming itself in its different functions and their structural demands uses or rejects that which is merely an expression of an individual's situation within him and around him. It resists the danger of being conditioned by the situation of self and the world in existence. It considers these conditions as material which reason has to grasp and to shape according to its structured laws". (p.93)

The Virtuous Nature of Autonomy

There are those who claim that autonomy is of itself a virtue, or therefore that it has intrinsic "moral excellence" (Chambers, 1983). So that those who claim that autonomy is a virtue are in fact saying that they want autonomy encouraged or maintained because of its intrinsic goodness. Kohlberg's (1981) work on moral development starts out with the Socratic question, "What is virtue?". The whole basis of Kohlberg's work was to try and work out if morality could be taught. He rejects the idea of teaching a "bag of virtues and vices" and so decides that the:

"... only constitutionally legitimate form of moral education in schools is the teaching of justice and that the teaching of justice in the schools requires just schools". (p.37)

He goes on to argue that the fundamental values of a society are termed moral and that these major moral values are the values of justice. It is claimed that the principles of

liberty and equality are those which would lead all rational people to moral agreement. Such a view still leaves the problem of those who disagree; it seems too easy to reject their views on the basis that those who hold such views are not rational.

To return to the question of whether or not autonomy is a virtue, there are others who, while acceding to the view that autonomy is a good thing, at the same time question the inherent quality of goodness. Gillon (1985), for example, rejects this notion of autonomy being a virtue when he reasonably points out:

"A villain is surely not rendered in any way virtuous by his autonomy. Rather, autonomy is a prerequisite for all the virtues in that these must ... be based on deliberate choice if they are to be virtues". (p.1807)

This means then that autonomy is not a virtue of itself but is intimately bound up with choices of good or bad activities. The burglar chooses to break into a house which is a bad deed for which the moral community demands he take responsibility.

Information

One of the important aspects of being able to deliberate or utilise reason in making choices is the need for information. Clearly this need for information is of importance in many fields but perhaps it has especial relevance to health care. For choices to be made in this area information must be given, since the bulk of the population does not collect such knowledge in the general way of living, and in some instances, what is even worse, the information a lay individual considers

to be 'knowledge' may be an incorrect understanding either in part or in total. Strong (1979) makes a plea for information to be given on the basis of what is needed by a reasonable man. Though this sounds sensible, it does mean that from the stance of the professional such knowledge, when claimed by the individual, must be checked out and possibly amplified, modified or corrected. Most health care professionals are all too ready to take claims at face value and not explore them.

There are, then, three recurrent themes in the literature on autonomy. Reason or thought is perhaps the most pervasive but closely allied to it there is intention or will and these two trigger action. These themes are seen as being affected by a variety of factors, such as capability, character and the exercise of the moral community which sets out the moral principles on which decisions are based. These aspects will not be further pursued here.

THE RIGHT TO AUTONOMY

The concept of autonomy is of such universal importance that this has led to the talk of a right to autonomy. If there is a right, then there must be a corresponding duty or responsibility. Part of the difficulty of a right to autonomy in the health care context is that this leads to moral dilemmas, sometimes between two patients' autonomy and sometimes between the autonomy of the patient and the autonomy of the professional.

The weight to be given to the autonomy of one patient against that of another would lead to potential difficulty. Henrich and Pacini (1983) point out that there are inherent difficulties in speaking of rights at all when they say:

"... norms with a claim to validity and universality; ... when every effort has been made to show that such claims can be rationally justified on the basis of universal principles alone; ... when, in fact, there is strong evidence to show that human rights today are set in a wholly different global context". (p.255)

Only with dramatic closing of the differences between races and conditions of men:

"... and under new and unpredictable conditions, could the language of the 'rights of man' recapture the resonance and fullness of meaning that possessed those who first championed rights in modernity".
(p.275)

The seeming inappropriateness of the rubric of rights leads to another attempt to find a way of recognising the importance of the concept of autonomy in practice. Various writers have moved from using the phrase "concept of autonomy" (which surely means the idea of, or ideas about, autonomy) to stating the principle of autonomy. The use of the word "principle" implies taking the idea or concept and introducing a moral element which involves an 'ought'. Autonomy then becomes an imperative. Thus the demand that one ought to exhibit and exercise autonomy means that everyone has a responsibility to elicit and follow all examples of autonomy. But, in contemplating the diversity of people's abilities and circumstances (there are those who cannot communicate their

wishes, others who may not understand language at all, yet others who have no physical power and more who are financially disadvantaged), this idea would appear to be fallacious.

There are, however, writers who, having taken all these caveats into account, have pointed out that there ought to be concern with the principle of respect for autonomy. They point out the truth of a generally experienced desire to have one's views taken into account while accepting that there may be autonomy in different degrees. This is the reason why it is important to accept the autonomy of other people (Gillon, 1985; Fromer, 1981; Beauchamp and Childress, 1983). Such a view helps protect the importance of individual autonomy.

THE MORAL JUSTIFICATION FOR CARRYING OUT HEALTH CARE

Some of the thinking about the moral justification for carrying out medical care was underlined and dramatised by the involvement of doctors during the 1939-1945 war. This thinking focused specifically on the principles involved in research involving human subjects (Engelhardt, 1973).

Agapeistic Theory

Historically, it could be said that the moral theory underpinning nursing care was the agapeistic theory. The word 'agapeistic' arises from the Greek word meaning caring love. Here the view is that man's ability to love is paramount rather than his rationality. St. Augustine was most influential in the rise of such a view. Love is the basis on which specific judgements are arrived at. The decision chooses what is the

most loving thing to do in the circumstances. Another form of this theory, devised in modern times, is labelled situation ethics, where each situation is judged solely on its own merits in the light of the judge's personal commitment to love (Fletcher, 1966).

Utilitarian Theory

Another option would be the utilitarian theory (Warnock, M., 1962). This arises from the work of both Aristotle and Mill. Man is seen as having a built-in tendency to strive towards his fulfilment as a human being and of his physical, emotional and intellectual faculties. The goal which governs this theory is the pursuit of happiness. Theories which interpret the pursuit of happiness as a chosen rational goal of human society have been called utilitarian because the usefulness or value of an action or policy is determined by whether it adds to the sum total of human happiness. This would seem to provide a perfectly reasonable explanation for the provision of nursing care. One branch of utilitarianism tries to determine in a particular situation which course of action will bring the most happiness, or at least the least harm and suffering to individuals.

Deontological Theory

The third possible theory is a deontological theory arising from Kant's work. Here the view is not the end or consequences of an act which makes it right or wrong but the moral intention of the agent. It is said that human actions cannot be consistently rational unless they obey rules which

are universal. From deontological theory we get the concept of duty, where the moral intention of the agent is to care. It is probably this last theory that most nurses will base their work on.

MORAL PRINCIPLES

Within any of the theories there is need to base our decisions on moral principles. The Belmont Report (1978), which was produced by the National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, enunciated ethical principles and guidelines for the protection of human subjects of research. Though these principles were enunciated particularly with research in mind, nursing equally bases its care on principles and those suggested suitably underpin the care of people in this related area. The Report listed three ethical principles among those generally accepted in our cultural tradition, namely: beneficence; justice; and respect for persons. These three principles have been used by others, such as Thompson et al (1983), to stimulate and organise thinking on ethical matters for nurses.

1. Beneficence:

Beneficence covers acts of kindness that go beyond true obligation. The document states:

"Two general rules have been formulated as complementary expressions of beneficent actions in this sense: (1) do not harm and (2) maximize possible benefits and minimize possible harms". (p.6)

Certainly this seems to be a suitable, not to say laudable, principle on which to base nursing care since it is unthinkable to set out to harm others.

2. Justice:

Justice indicates the division of care equally or at least equitably. Obviously when thinking about nursing care justice seems to be an impossible aim since each patient is not given equal care, or even equal time or effort. The Report points out that there are several formulations of what they see as being just ways to distribute "burdens and benefits". It lists these as:

"(1) to each person an equal share, (2) to each person according to individual need, (3) to each person according to individual effort, (4) to each person according to societal contribution, and (5) to each person according to merit". (p.9)

There are many nurses who would rebel at those formulations as means of allocating nursing care, especially within a National Health Service, but the principle remains important.

3. Respect for persons:

This leaves the third principle, respect for persons. The Report says:

"Respect for persons incorporates at least two basic ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection". (p.4)

This principle seems to fit the concept of autonomy particularly well but it needs to be explored a little further.

It is respect for persons which protects the dignity of man as man. Persons are respected because they are such, but what makes human person persons is difficult to tease out. Fletcher (1974) made an attempt to define personhood. He listed positive and negative criteria. There were fifteen positive and five negative criteria in his list. A couple of years later, after much discussion, these criteria had been refined and were stated as four indicators, namely: neocortical function; self-consciousness; relational ability; and happiness. The 'happiness' indicator provides many with difficulty since it is almost impossible to identify such an emotion in other people, or to agree as to the degree which would be accepted as norm. For others, however, these indicators may be insufficient.

Downie and Telfer (1969) analyse the principle of respect for persons by using the notion of "the distinctive endowment of a human being". That special endowment for them is the "practical exercise of reason" which they describe as:

"The ability to choose for oneself and more extensively to formulate purposes, plans and policies of one's own. A second and clearly connected element is the ability to carry out decisions, plans or policies without undue reliance on the help of others". (p.20)

These facets of the human person are not quite enough for nurses since many patients, like the foetus, the mentally handicapped, the severely mentally ill or the unconscious, often do not exhibit them. This calls for further exploration of what makes a human being human. From the earliest times the 'specialness' of man has been a matter of moment. Sophocles (1971) writes:

"The world is full of wonderful things
But none more so than man". (p.203)

The Judaic tradition expresses that uniqueness in such statements as:

"And God created man in his own image, in the image of God created he him; male and female created he them".

(Genesis 1v27)

Christian theology has built on that tradition and theologians have given various interpretations of personhood. Zizioulas (1975), for example, speaks of the relationship between God and man and of the idea of Christ being God and man, viewing his personhood being bound together with nature since the 'person' can only be known in relationship. One of his most intriguing paradoxes is that "the presence of being in and through the human person is ultimately revealed as an absence". This idea is understandable; for example, when a loved one leaves or if an attempt is made to meet someone who is not there, "the presence" of the person is made more potent in absence, and indeed the reality of the person may be revealed. There are, however, many who are uncomfortable with such overtly religious views of 'otherness' but yet would want to express some dimension of specialness in man. For those who need something else, perhaps the idea that Macquarrie (1982) calls "transcendence" would help. Macquarrie speaks of transcendence in terms of exceeding the limits or going beyond:

"There are many ways of transcending. Involvement in the world around us, relations with other people, religious or political commitment are all modes of

transcendence ... Transcendence means pushing back the horizons of humanity itself". (p.26)

Cassel (1982) has commented in a fascinating essay on suffering that health professionals actively contribute to the suffering of patients by not knowing what constitutes personhood and not respecting the capacities inherent in the specialness of man.

Some writers, such as Gaylin (1984), while accepting that man is different from the animal kingdom, claim that autonomy is the concept which most easily expresses that uniqueness. Many who may not act on this concept nevertheless have sought attributes which they feel "dignify and elevate our species". But they have not made clear what is the underlying principle which invokes care on behalf of others.

Respect for persons as a basic moral principle would seem to hold not only for the relatively fit patient, but (if it includes some idea of transcendence, as an explanation of the individual being of supreme worth) also for those at the margins of life (the sentient elderly or the foetus), as well as those who are physically, mentally, socially or emotionally handicapped.

It has been suggested that autonomy is an important concept for individuals, and having made a plea that since that is so, there requires to be a principle of respect for autonomy which can only operate if it is held within the principle of respect for persons. Exploration is still needed of why it is important to the carrying out of nursing care.

WHY IS AUTONOMY IMPORTANT IN CARRYING OUT NURSING CARE?

The review of the literature on autonomy has shown that autonomy of thought, will and action are important for individuals who are mature, rational and able. This, of course, has already been seen as a difficulty for those patients like the unborn, infant, physically disabled, mentally handicapped or mentally ill.

Paternalism

How can nurses continue to carry out their nursing care while practising the principle of respect for persons within a deontological theory? In such situations people tend to act in a paternalistic manner. That is to say, they ignore the whole concept of autonomy. They behave as the parent of the infant and make all choices on his behalf. When autonomy recedes, paternalism advances and vice versa. Paternalism looks after the patient's interest in place of autonomy. Childress (1982) differentiates between types of paternalism. He cites:

"'Limited paternalism' overrides a person's wishes, choices and actions for that person's own good because he or she suffers from some kind of defect, encumbrance or limitation in decision-making or acting ... 'Extended paternalism' overrides a person's wishes, choices or actions because they are risky for that person ... 'Positive paternalism' involves the promotion of good while 'Negative paternalism' involves the prevention or removal of evil ... 'Direct paternalism' in which a person whose benefit is intended is also the one whose wishes, choices and actions are directly overridden ... 'Indirect paternalism' e.g. if we ban a product such as cigarettes in order to prevent harm to users we restrict

the actions of growers of tobacco and manufacturers of cigarettes not because they are harmed but because users are harmed". (pp.17-18)

Culver's (1979) definition is clear and general. It states:

"A is acting paternalistically towards S if and only if A's behaviour (correctly) indicates that A believes that:-

- (1) his action is for S's good;
- (2) he is qualified to act on S's behalf;
- (3) his action involves violating a moral rule (or will require him to do so) with regard to S;
- (4) S's good justifies his acting on S's behalf independently of S's past, present, or immediately forthcoming (free, informed) consent; and
- (5) S believes (perhaps falsely) that he (S) generally knows what is for his own good". (p.2)

While paternalism is clearly important and necessary in some instances (as in the case of the infant who cannot make decisions), there are examples when, because of illness or institutionalisation, patients have acquiesced in an inappropriate way and no one has questioned the action. There is also a difficulty of knowing what is the appropriate model to adopt in the doctor-patient or nurse-patient relationship.

The Role of the Nurse

It is obvious, then, that there are times when paternalism must be practised, but what the nurse's role in it is needs some thought. The days of claims about a holistic approach to nursing are mercifully with us (Henderson, 1966). Whatever shape that holistic approach takes, it is done within a context of roles. How nurses see themselves is very important. There is

a long history of that relationship being described by various metaphors. Winslow (1984) lists surrogate parent, nun, domestic servant, handmaiden of the physician, even professional contractor, as ways in which nurses have either been seen or see their role. Models of the specific relationship between nurses and their patients have been devised by nurses in an attempt to explain the situation as it is, and to suggest changes which will bring improvement as the writers see the need. Murphy (1979), for example, suggests a move from a "Bureaucratic Model" to an "Advocate Model". This she sees as being a means of enhancing understanding and improving care given to patients by nurses and doctors. As a development of these ideas, Gadow (1980), in her article entitled 'Existential Advocacy' makes a plea to reject paternalism as well as advocating that nurses are more than champions of the rights of patients.

Patient Advocacy

Gadow (1980) describes existential advocacy in three ways:

- "- the nurse's assistance to individuals in exercising their right of self determination, through decisions which express the full and unique complexity of the values;
- a mode of involvement with persons which necessarily engages the entire self of the nurse;
- assistance to patients in unifying the experience of the lived body and the object body at a level that incorporates and transcends both". (p.55)

She claims that it is because of the nurse's close and repeated contact with the patient that such a helping view of advocacy is possible. But ultimately her ideas arise from rights and are

applicable to patients who can communicate and do have an ability to define what sort of decisions they are making and to ponder the principles as well as the history of the events which have led to the decision as well as the consequences of those decisions.

Such an idea makes very good sense for many nurses and patients, though there are many British nurses who would find such a role a very difficult one to adopt. But doubtless if they could be convinced that it were important they would try. The implications for patients in this country might be equally a problem. For those patients who cannot or will not take part in such a process the concept of advocacy falls, as does the strident demand for rights of autonomy. If the basic principle on which nurses must care is that of respect for persons, then such a respect will allow one to be sensitive to the needs of the whole person. That interpretation will include the quality of transcendence and will allow the ability to see a foetus as a potential person; or in the severely handicapped patient the mark of something greater than appears to be obvious; or in the sentient elderly patient a past.

MacIntyre (1983) suggests that nurses need to be:

"... interpreter or translator, as emissary between two cultures, that of the patient and that of the physician and surgeon".

He goes on to claim that such a role would require changes in nurse education:

"For it suggests the need for a kind of sensitivity to questions concerning communication of a variety of kinds, to



uses of language, to the relationship of body and mind, which have been the concern of philosophy and of literature".

(pp.82-83)

As we shall see, many of the ageing are among the most vulnerable and nurses, if they are to give individualised care to patients as well as make intelligent use of a complexity of scarce resources, will need to be sensitive to autonomy, its evidences in individuals and their own role as translators.

Autonomy of thought, will and action have great importance to the individual and his well-being. Some have said that it is indeed the expression of the individual. It is because of the central importance of this that nurses need to carry out their work within the context of the principle of respect for persons. The main themes in the literature about autonomy are rationality or thought, intention or will, and action. The means by which we decide what to do are complex and are affected by a number of influences. The desirability of making choices is important and has led to the assumption that there is a right to autonomy. Here it is suggested that rather than a right to autonomy, there is a respect for the principle of autonomy. Nurses have been seen to be important in the treatment of this concept if they base their work mainly on the principle of respect for persons which has autonomy at its heart.

AGEING

OVERVIEW

In the second major section in this review the subject of ageing is examined. Expressions of autonomy are not static and therefore change over time. The study was grounded in the experience of decision making in elderly people. People also change over time and so this section sets out literature which helps explain the ageing process. There follows some suggestion of the historical origins of attitudes towards, and care of, the elderly. This section is completed by drawing attention to the individuality of elderly people.

INTRODUCTION

Discussion of autonomy and its relevance to the provision of health care having been left aside for the moment, there is need to look at a group of individuals where the evidences, or their lack, of autonomy can be seen. It would be a salutary exercise to try and imagine what is meant by the elderly. Many have offered views to guide the thinking, such as Gray and Wilcocks (1981), Hodkinson (1975) or Binstock and Shinas (1976). As has already been noted, the label 'elderly' covers a large and growing section of the population. Labels, though useful, can be misleading; and this is particularly true of those related to age. In the case of children, for example, gradations are used which are commonly understood and they almost always relate to developmental gradations. So it is with the elderly, where terms suggested by Neugarten (1975) such as

the 'young elderly' and the 'old old', are now in vogue. Such labelling is used not merely to connote age but also stretches to include ability, either mental or physical, when terms such as 'fit elderly' or 'frail elderly' are employed. The inherent difficulty our society experiences in agreeing about gradations of ageing arises from lack of agreed definitions. With children the labels connote development and growth. Perhaps the almost euphemistic nature of the labels applied to the older age groups shows, at least tangentially, the commonly held view that old age is not a period of development but rather of deterioration.

Time was when to describe someone as old denoted a person who was very nearly at the end of life. Now an old age pensioner, especially if female, may well be embarking on a 20-30 year span of life. The inappropriateness of such labels should lead to a realisation that the elderly refers to a diverse and non-cohesive group. It is this very diversity which makes for the complexity of facilities and services required to care for this group. Another important facet of this diversity in the carers, professional and lay, as well as in the individual elderly person, is what connotation he perceives in the label. Such a connotation may be coloured far more strongly by experience than by knowledge and understanding of ageing.

THEORIES OF AGEING

Before one can seek solutions to the problems of the elderly there has to be agreement about what it is that is

being studied, and some frameworks and theories have been suggested to help with organisation and interpretation of data about ageing. Social criteria such as class structure; age; rural or urban dwelling; degree of industrialisation and changes in family patterns; and degrees of population mobility have been used as a basis for studying the older age group. Though these have produced useful information of a descriptive nature, they have not permitted any definitive causal relationships to be established (Central Statistical Office, 1975) and so more specific theories from different sciences have been sought to try to give greater understanding of the ageing process and its effects on the individual's previously "normal life".

Biological Theories

Most people find it possible to estimate the age of an individual person reasonably accurately by using a variety of clues. In addition to personal knowledge of older people, which may render a certain expectation, it is generally deviations from our accustomed norm in an individual's mental agility and/or physical mobility which leads to errors in the estimates. Although, for example, the French cellist, Paul Tortellier, who is in his seventies has not lost his skill in cello playing, his mobility, or his verve for life, nevertheless, with his mane of white hair, and creased face and hands, few would assume him to be in his forties.

The main thing to remember is that, as Strehler (1977) pointed out, there is a logarithmic increase in prospective

death with each passing decade. This would lead to the supposition that everything was on a downward spiral, and to some extent that is what the biologists and physiologists accept.

There are various versions of genetic models. Hayflick (1977), for example, noticed that various species have apparently idiosyncratic life spans. He goes on to note that if heart disease, renal disease and malignancies were to be eradicated, then the life expectancy would rise only by five years. It has also been noted that women live two to seven years longer than men.

Another area which one's genetic make-up seems to influence is that of arteriosclerosis and, some claim, Alzheimer's dementia (Jarvik, 1975). Hayflick (1977) has done work which demonstrates that cells only divide a certain number of times, but the interesting thing is that the number of times is apparently directly related to the age of the person whose cells they are. Comfort (1970) suggested a factor in the cells' death is accumulated damage (noise, as some writers refer to it) to the DNA or RNA within the cells. Damage also occurs when the genetic information needed for the synthesis of some proteins 'runs out'. Another source of change, according to Marx (1974), is an accumulation of waste products in the cell. These waste products are the result of metabolic processes of the cells but also can arise from environmental sources. Vitamin E has been demonstrated to increase the number of divisions the cells are capable of before they die.

There is a wear-and-tear theory which is appealing to the public mind. The comment that "so-and-so just wore himself out" exemplifies this. The structures of the cells are seen to have been so damaged that this has led to malfunction, or indeed non-function, to such an extent as to question life being sustained. Indeed all individuals lose 20% to 40% of their brain cells during their lives (Brody and Vijayashankar, 1977). This is possibly another explanation of wear-and-tear, and certainly would provide a reason for diminished brain function.

Other writers have suggested that the ageing process is due to the autoimmune system being affected. This results in the body's ability to repel and fight infection being inhibited (Finch, 1977). Some suggest that the fundamental item is stress and that it is that which is critically affected by age.

The physiologists have also found alterations attributable to age such as basal metabolic rate and total body water, muscle changes as well as the cardiovascular system (De Vries, 1975). Perhaps the most important change that has been noticed with age is that it appears to take the body longer to return to normal functioning after a stimulus, like the blood sugar after an IV injection of glucose. This seems to be a similar stress explanation to the one already mentioned.

Of course it is well recognised that hearing, sight, smell and taste also diminish with age. Such explanatory factors as these biological and physiological ones have suggested a theory of chronicity in which individuals move along a continuum of increasing decay until death must follow (Upton, 1977). The

chronicity not only indicates ageing per se, but also the increasing incidence of disease with long-term disabling effects. The increasing technical abilities in medical science which allow doctors to resuscitate, maintain life, or carry out complicated surgical procedures such as organ transplants, have led to a feeling that every effort, no matter what the consequences, must be made. The gentler, more mellow and possibly humbler stance of the Hippocratic Oath, or as Clough puts it in his verse, "Thou shalt not kill; but need'st not to strive officiously to keep alive", has been left behind. This modern attitude to medical care, in which some nurses are caught up, leads to the increasingly common reality of the elderly being condemned, inappropriately in some instances, to long-term hospital care.

Other writers (Vischer, 1966; Pruner, 1974) have felt that these physiological theories, though important, are not sufficient, since the explanation for ageing is a much more complex issue than can be explained by physiological reasons alone since these deteriorations do not occur at any specific age, unlike children who have developmental 'norms'. The influences of the physical changes already discussed, as well as the cultural expectations and possibilities together with the social framework in which the elderly person lives, are each important factors which continue to form theory. These writers have produced theories of "social gerontology".

Social Theories

It is interesting to see that the philosopher's view of the importance of personality in making decisions has been reflected by sociologists such as Havighurst (1968), who thinks that the personality of individuals is accentuated by age and indeed "those values the individual has been cherishing become even more salient".

It has been noted that there are three aspects of looking at the personality. The first is the environment in which the person operates; secondly, the person; and, thirdly, how the person relates to other people and the environment in which he lives.

The first area, then, is the environment in which the person finds himself. Chisholm et al (1982) have shown that there is a prevalence of confusion in hospitalised patients. The sort of architecture, for example, high-rise flats, exacerbate anxiety and depression. It has also been said that after a bad summer most people feel less well and ready to cope with life.

Barker and Barker (1968) showed that older people were restricted in the number of places in which they met other people or spoke to them. In Goffman's (1967) work it was clear that in institutions where the person has little or no control over what happens or when activities happen, people become more and more frustrated which adds to their vulnerability to discipline and harsh treatment which sets up a 'Catch-22' situation.

The second area relates to the individual and his characteristics. There has been quite a lot of work done on particular traits, such as, for example, cautiousness. Botwinick (1978), however, showed that the idea of caution can only be applied to certain situations and cannot be applied across the board. Certainly there are many old people who are more adventurous than younger people. Sex-role related behaviour has also been widely studied. Zarit (1980) reports work undertaken along with Cherry which has attempted to uncover whether people see themselves as both male and female, and the implications of that view. One study suggests that changes in personality in the elderly have much more to do with the health of the individual than with the ageing process (Schwartz and Kleemeier, 1965). This is perhaps the area of the understanding of ageing which is least understood and researched, just because it is so difficult to contrast and compare individuals and their individual experiences over time.

The third area of theory relating to society which impinges on ageing is where the individual relates to the other people who inhabit his world. Cumming and Henry (1961) suggest that with ageing there is a mutual distancing or "disengagement" which results in a diminution in the interactions between the older person and the social system to which he belongs. The disengagement is often accompanied by an inward-looking personal pre-occupation. People who are so described, almost by a self-fulfilling prophecy enhance the disengagement. With a slightly different slant, Runciman (1966)

talks of "relative deprivation" which arises when elderly people are divorced from social arenas by retirement or failing health. Such divorce not only limits social contacts but also results in a diminished financial income which can further speed the isolation. Others have stated, however, that by keeping active and interested, the older person need not leave the social scene (Blau, 1973).

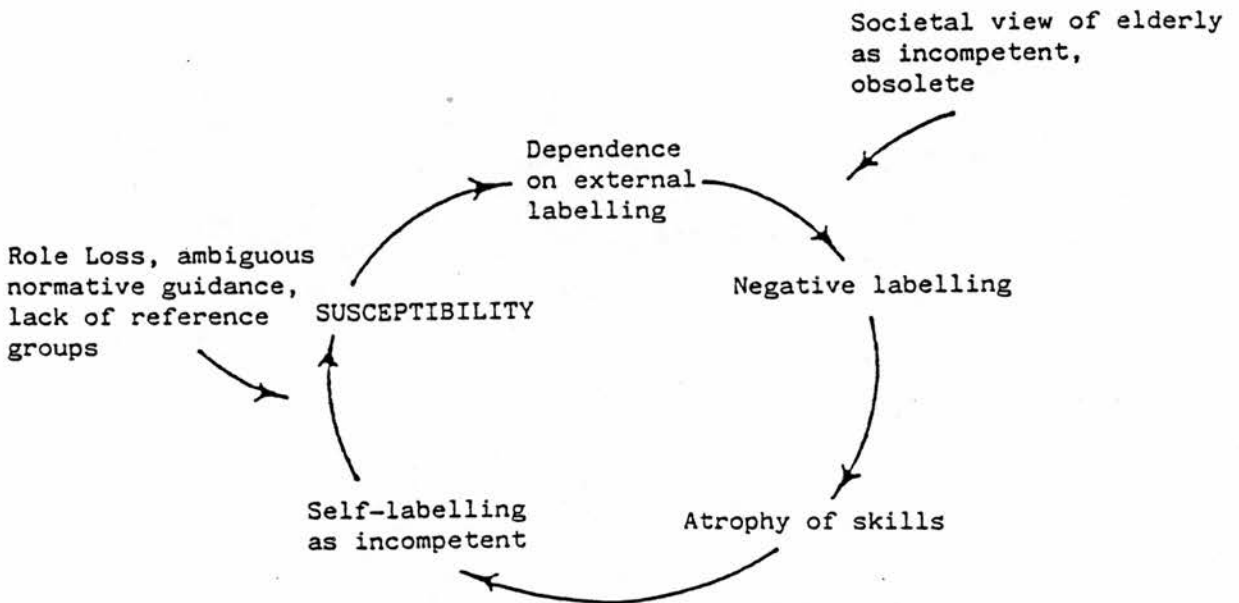
Kuypers and Bengston (1973) felt that social-psychological models of ageing such as stress theory, disengagement theory or activity theory did not suitably explain the changes which took place in the behaviour of elderly people. The social breakdown theory, based on work by Greenberg and Zusman, used a seven-step formulation which demonstrates "negative psychological functioning". The seven steps are:

- (1) Precondition of susceptibility.
- (2) Dependence on external labelling.
- (3) Social labelling as incompetent.
- (4) Induction into a sick, dependent role.
- (5) Learning of 'skills' appropriate to the new dependent role.
- (6) Atrophy of previous skills.
- (7) Identification and self-labelling as 'sick' or 'inadequate'. (p.187)

This theory explains three important areas in the social psychology of ageing, namely the relationship between the elderly person and the social environment in which he lives, the response of feelings of competence or well-being and the

feedback which leads to the setting up of a vicious circle. The social breakdown syndrome is exemplified thus (Figure 1):

FIGURE 1: A systems representation of social breakdown syndrome as applied to old age with negative inputs from the external social system
(From Kuypers and Bengston, *Social Breakdown and Competence in Human Development*, 16: 190, 1973)

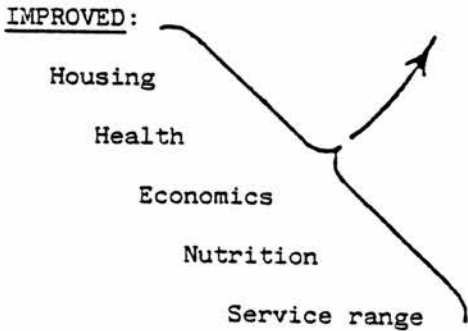
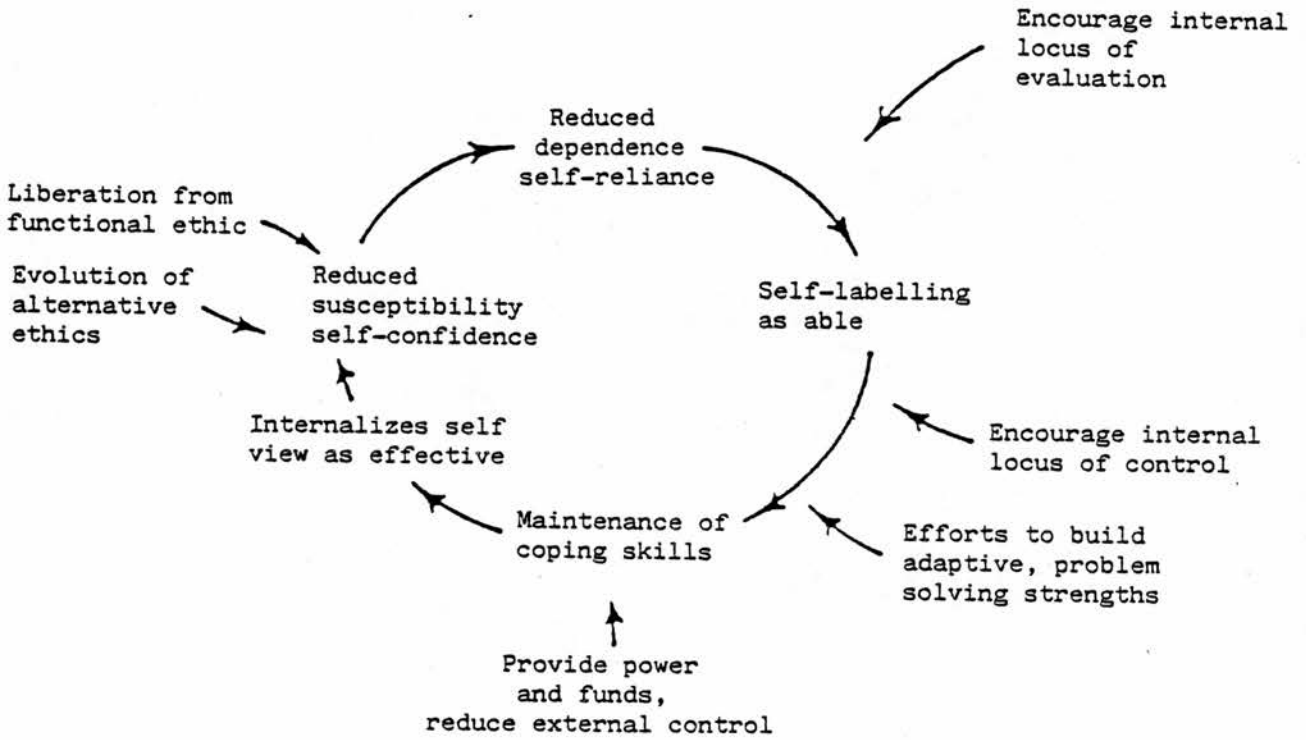


These writers use performance in social positions within society, an ability to cope with the setting and "feelings of mastery and internal locus of control" as definitions of competence. They offer various possibilities. The claim is made that there needs to be a liberation from a "functional ethic" which, along with the "evolution of alternatives", will reduce

the likelihood of self-confidence being dented and which in turn will improve self-reliance. This will be helped by the individual evaluating his own worth rather than having an external societal view imposed upon him. To preserve the idea of being "able", the individual needs to maintain an internal locus and to find coping strategies. The authors state that improved housing, health, economics, nutrition and services will consequently provide power and funds, and thus reduce outside control over the individual's life. Kuypers and Bengston write from an American stance but, as has already been noted, at least some measures to attempt the preservation of independence in this country are secured by the National Health Service, old age pensions and public housing policies, as well as Social Services with help from community services. Such means interrupt the vicious circle and so should increase, enhance or merely maintain competence and thus produce a "benign cycle" (Figure 2).

Kuypers and Bengston are not overly specific as to how exactly these changes could be implemented, though there is a clear emphasis laid on self-determination and keeping active to stave off a dependent old age. Johnson (1982) explains what "more active" means for him. Clearly its most important element rests with physical and psychological fitness.

FIGURE 2: A possible social reconstruction syndrome
 (From Kuypers and Bengston, Social Breakdown and Competence in Human Development, 16: 197, 1973)



Theories of Growth and Development

Though theories with a biological basis are important in trying to explain the vagaries of age, those of personality also have relevance, while those of a psychosocial dimension help to underline the many faceted nature of the problems of ageing. How our understanding is advanced to make possible the elderly being heard is perhaps only possible if help is given to review notions of ageing being seen as a period of decline. Rather than pursuing a continuum of inevitable deterioration, ideas of growth and expansion, or at least change or accommodation (all aspects of development), have found acceptability. Development is a view of life and living that mirrors nature. This is clearly described by Wendell Holmes (1976) in his poem, 'The Chambered Nautilus', where the need to accommodate growth provokes the onward movement and the building of a suitably enlarged chamber within the shell in which the Nautilus resides until the next move is needed. The notion of progressive development which continues growth with experience and its inherent consistency is an attractive one since from early times this notion has made sense. Individual experience is preserved and enhanced within a unique context.

Shakespeare, in 'As You Like It' (various editions), speaks of the seven ages of man. In this, man, when he reaches old age, returns to a:

"Second childishness, and mere oblivion
 Sans teeth, sans eyes, sans taste,
 sans everything".
 (Act II, Scene vii, Lines 165-166)

Many others since have used the analogy. An example is Nicholson (1980) who organised his research report under the following seven titles:

- (1) The discovery of childhood.
- (2) Finding yourself.
- (3) Getting it together.
- (4) Life assurance.
- (5) Taking stock.
- (6) Winding down.
- (7) Life after work.

In the last section, Nicholson speaks of the elderly being pre-occupied with death, and being alone and lonely which therefore raises the problem of how society responds to its responsibility of providing care to the old. This sort of interpretation, like Shakespeare's, is rather pessimistic for, though it is cyclical (in that the metaphor of an egg shape is used), it has little retained consistency since the theory seems to be that once a peak is reached, then the cycle is necessarily downward until eventually babyhood is reached for the second time. While that can be seen as the experience of some, it is by no means universal. As a theory, then, though it points in a sensible direction, it does not appear to be complete because it ignores the uniqueness of, and differences between, individuals. The desire to further the idea of development, therefore, remains as a basis for greater understanding of ageing, but with an increased focus on the individual and his place on a continuum with poles of

dependence and independence rather than chronological age. Individuals moving from birth through adulthood to old age may find themselves moving back and forth on such a continuum as they experience age, illness or other crises, rather than an inexorable cycle of dependency back to dependency.

If consideration is given to why one does certain things, then the past and more recent experiences have a greater influence on development than genetic make-up or our early nurture. Karl Popper (1977) says:

"... I suggest that being a self is partly the result of inborn dispositions and partly the result of experience, especially social experience. The newborn child has many inborn ways of acting and of responding, and many inborn tendencies to develop new responses and new activities. Among these tendencies is a tendency to develop into a person conscious of himself. But in order to achieve this, much must happen".

(p.280 in A Pocket Popper,
Miller, D. (ed.), 1983)

Others, including Freud, but notably Erikson (1980), have attempted to explain development in a life cycle mode. This holds these various ideas together, suggesting an inborn quality which it develops by experience to full maturity in adulthood and into old age through stages. Erikson's (1978) developmental approach arose out of observation of children, including their genetic as well as their social possibilities. He stated:

"... in developing or contributing to an inclusive human psychology, psychoanalysis can not shirk the task of accounting not only for the way the individual ego holds the life cycle together, but also for the laws which connect generational cycles with individual ones and the social process with both". (p.23)

Erikson, in devising his view of the life cycle, used eight different phases of ego development. Each stage is conceptualised by pairs of alternatives towards life, the self and other people. From a successful growth emerges what he calls a "virtue". The plan is set out as follows characterising a stage of age which is expressed as:

- **infancy as basic trust versus mistrust-hope**, which is defined as "the attainability of primal wishes, in spite of the dark urges and rages which mark the beginning of existence";
- **early childhood as autonomy versus shame and doubt-will**, which is "a sense of self-control without loss of self esteem is the ontogenic source of a sense of free will";
- **play age as initiative versus guilt-purpose**, which ensures "the courage to envisage and pursue valued goals uninhibited by the defeat of infantile fantasies, by guilt and by the ... fear of punishment";
- **school age as industry versus inferiority-competence**, which is the "free exercise of dexterity and intelligence in the completion of tasks unimpaired by infantile inferiority";
- **adolescence as identity versus role confusion-fidelity**, which is the "ability to sustain loyalties pledged in spite of the inevitable contradictions and confusions of value systems";

- **young adulthood as intimacy versus isolation—love,** where "intimacy tests the firmness of the identity established, for deep involvement with another demands the strength to put one's own individual identity at risk";
- **maturity as generativity versus stagnation—care,** which is "the concern in establishing and guiding the next generation";
- **old age as ego integrity versus despair—wisdom,** which is "the detached and yet active concern with life itself in the face of death".

An important element at this last stage is an acceptance of pattern in one's life, with regard to both its coherence and quality, and such acceptance forbids any frenzied attempt to make a major change at this period of life. On the other hand, despair is a response to potentials and goals which have not been achieved and because of diminished life expectancy are not likely to be achieved.

Stevens (1983) points out that Erikson was concerned to make clear that he was not suggesting an achievement scale:

"It is not simply that the positive pole of the pair is the attainment to be desired. All that Erikson will commit himself to is the desirability of establishing a dynamic balance of favourable ratio of the positive to the negative pole". (p.56)

Importantly, too, there is no inbuilt view that in old age there is an expectation of return to early childhood, rather that development is possible to the end and the "virtues" earlier achieved or exhibited are not lost but may be shown

differently as the "dynamic balance" is more or less achieved. All this can explain the movement, sometimes of fluctuation and sometimes of uncertainty, which is life.

The process by which the individual moves from one stage to the next is an interesting one. With the Nautilus it is merely a matter of increasing size which provokes the move to the next chamber. Humans, however, are more complicated for, though they increase in size, the factors which make for development have been observed for many years. Most have been seen in terms of crises. Van Gennep's (1960) seminal work in this field, 'The Rites of Passage', not only identified the various crises that man experiences but also the symbolic and ritual way in which he accepts their reality. Erikson (1975), too, in examining the lives of Luther and Gandhi, shows that the various crises they experienced made them the men they were, but also allows those who follow to understand them and appreciate them better. These ideas of development being the responsibility of crises or major events like having children, work histories or bereavement are all used by Nicholson (1980), Sheehy (1976; 1982) and Hardie (1983) as well as others.

Since there are dual foci of the study, namely the elderly and also the philosophical concept of autonomy, it is of interest to draw attention to another developmental scheme, one on which the psychologist, Kohlberg, has spent almost 30 years. An important influence on this work was that of Piaget (1963). His views of life cycle have been important because they have provided a guide to how children look at the world at different

stages of development as well as the relationship between their development of autonomy and "cognitive capacities". Autonomy in this instance refers simply to making decisions. Kohlberg's work was developed from study of a variety of students, including children, where theories of moral development and education could be tested. The results have been the basis of much of his teaching at Harvard University.

Great emphasis is laid upon cognitive abilities which make it possible to differentiate between the mechanism of the thinking process and the matter under debate. Kohlberg believes that the development of thinking happens in a constant series of stages, beginning simply but developing into increasingly abstract modes. His scale is value laden in that he appears to think more highly of the higher points on the scale and less well of the lower points. He does point out that, in general, few adults achieve more than the third level. He has used the concept of justice as the variable by which to understand the thinking process so that comparisons can be made. Clearly children can see the point of the "morality" of doing something or not when the threat of punishment is the consequence of an "immoral act" so that a simplistic idea of justice is the basis for choice. The adult, on the other hand, might be able to make decisions on the basis of contractual social agreements. For example, the Constitution of the United States of America, being based on the rights of individuals each having equal weight, can produce a more abstract kind of reasoning about justice. Discussion of cases resting on law from the

Constitution have been used as examples of how the "moral development" of individuals can be measured. The six stages of moral judgement are described as:

- (1) Punishment and obedience.
- (2) Individual instrumental purpose and exchange.
- (3) Mutual interpersonal expectations, relationships and conformity.
- (4) Social system and conscience maintenance.
- (5) Prior rights and social contract or utility.
- (6) Universal ethical principles.

Generally it has been found that people develop from one stage to another slowly and, as already noted, do not achieve the upper grades or levels, though it is possible to speed up the process if an intensive course in "moral education" is taken. Goldman and Arbuthnot (1979) agree with Blatt and Kohlberg's avowed aim of moral education as:

"... the stimulation to the next step of development rather than indoctrination into the fixed convictions of the school, the church or the nation". (pp.175-176)

Goldman and Arbuthnot (1979) have used the theory as the basis of teaching medical ethics. In commenting on their reported results of a very small sample (12 students), Gillon (1979) states various reservations he has about the theory itself as well as the results. Among these reservations, and to Gillon the most important, is an attempt to:

"... inculcate a specifically Kantian theory, with alternative ethical theories offered in descending order of merit below this. Such inculcation of specific ethical theories surely requires extensive philosophical justification". (p.181)

As far as the present purpose is concerned, it could be argued that most people, when contemplating what they have done in their lives, generally do not speak in terms of moral decision making and certainly few have undergone courses of moral education. Now that may be seen as a flaw in the education system of this country, though religious education may be at least an attempt to fill such a gap. The question is left, however, as to whether that is indoctrination of a certain sort and whether such training is the appropriate training to enable people to handle the problems or questions they might face in life. As already pointed out, Kohlberg, Goldman and Arbuthnot certainly agree that the stages are superior to each other and Gillon's point might well be valid, that is to say that some methods for coming to decisions are seen as being intrinsically better than others. One could agree that whatever decision a person comes to about himself is right for him provided he has had the options explained to him, which of course is the basis of informed consent. If that is so, does it really matter by what means or what philosophical basis he reaches it?

ATTITUDES TOWARDS THE ELDERLY

There is a societal assumption that the need to care for the elderly person who is alone and with little or no income is a new phenomenon since the extended family is now much less and people live to a greater age. Too, there is a widespread feeling that because of changes within family patterns,

arrangements for caring for the elderly are more difficult and more stressful than in past times. The factors of aloneness and having a small income are among the most potent in the assimilation of the power to make decisions for other people.

Historical data do indeed bear out the fact that there have been changes in family patterns but they are not quite what the myth has led us to believe. Stone (1979) suggests that it would appear that the present-day acceptance of divorce is merely the modern equivalent of death. Whereas in days gone by the shorter life expectancy resulted in marriages of possibly ten or less years, now it is becoming increasingly common for marriages to last 50 or more years. Thus the greater length which marriages last, particularly after the last child has grown up and left home, has provoked the acceptance of the institutionalised break of the marriage bond by divorce rather than the natural break by death.

Certainly divorce was not acceptable in the Victorian era and so the people who are now very old and therefore grew up then may have difficulties with what might be seen as an example of wicked and irresponsible youth. The Victorians took marriage as an awesome commitment which lasted "till death do us part", an attitude which they see as not being shared by their children and grandchildren. It must also be noted that in fact the number of divorces happening after 25 years of marriage is rising, though often to be replaced by another relationship.

In earlier times, when life span was short, there was much remarrying and very complicated family groups of step-children. Stone (1979) claims that in the 17th century, when there was a high adult mortality rate, only about 5% of the population was over the age of 60. He goes on to state that:

"Among the will-making part of the population, bereaved parents were obligatorily looked after by children. So long as they did not remarry, most widows had a legal right to a room and board, and access to the communal fire, in the house of their eldest child. Widowers also seem to have been 'sojourners' in their son's houses". (p.48)

Boyd (1980) shows that a similar commitment was expected of families in Scotland in the same period and later. His data do not make clear, since he was using mainly church records, how the care of the elderly worked. It was a period in Scotland when marriage was not much embraced because of the lack of income or housing. In times of great poverty it was very often the grandparents who had responsibility for their unmarried daughters and their children rather than the reverse. It is possible that, though care for the elderly was seen as a duty, the pragmatic resolution was that it was more important to look after the young who were the next generation and death would help look after the old.

The 18th century brought its own changes. There was a decline in the position of patriarchy. Stone (1979) concludes that the rise of individualism, in the sense that each person had to make his own way and be self-reliant by means of earning or at least being self-sufficient, led inevitably to the

elderly losing authority since their opportunity for looking after themselves in a material way was diminished. If this is so, probably not a lot has changed in the sense that individualisation in terms of personal responsibility is still rampant and the elderly are still losing authority.

In the past, when sojourning was a matter of course, the sorts of decisions that the sojourner was involved in were probably not of the day-to-day nature of, for example, how to spend money and what social contact to pursue. In effect it was like being a permanent visitor in another house. But with the rise of individualism the expectation might be greater that ordinary decisions should remain part of life. Such a state must provoke a sense of confusion in the elderly. On the one hand, the elderly person is expected to make all his own decisions, while at the same time society has the idea that the elderly are incapable or that it is inappropriate for them to make decisions at all, or that decisions are negated by the loss of position.

What is meant by individualism varies from society to society. As has already been noted, there are many factors that in our society led to our acceptance of this idea. These include the alluded to social changes, but also important was the Reformation which laid stress on the propriety of a direct link between God and man rather than the relationship being mediated by the Church, its clergy and the saints. These factors were used during the industrial revolution when emphasis was laid on the individual being able to climb the ladder to social and financial security by his own hard work.

Such efforts militated against the handicapped, the frail and the old. Since it was only by work that an individual had a place in society, those who could not work fell foul of the system. In Scotland, medical care took a "back seat" to education in the dealing out of money for the poor in the 19th century. There was new Poor Law legislation in 1845 which did help provide care. Hamilton (1981) points out that:

"In Scotland, this system (workhouses) was not in use and the poorhouses continued to admit only the old, feeble and sick. Not until the end of the century was any help given to the unemployed and only at this later date were some unemployed persons admitted for a short period to the poorhouse to check their sincerity and their destitution". (p.228)

Legislative measures were enacted following the Poor Laws as well as other factors which Pater (1981) cites as being:

"... philanthropic movement of the eighteenth and early nineteenth centuries which gave birth to the voluntary hospitals ... another was the sanitary revolution in the mid-nineteenth century ... the first public housing ... the provision of isolation hospitals for smallpox and other infectious diseases ... the introduction of the services for the health of schoolchildren ... stimulated by public concern at the physical shortcomings of recruits to the army during the Second Boer War". (p.2)

Bevan's proposals for legislation answering the needs typified in the 'Five Giants':

- (1) **Poverty**, which was to be answered by social security, insurance and pensions;
- (2) **Squalor**, which was to be answered by new housing policy;

- (3) **Disease**, which was to be answered by the National Health Service;
- (4) **Indolence**, which was to be answered by the eradication of unemployment; and
- (5) **Ignorance**, which was to be answered by a new education policy;

were implemented in 1948 to provide varied services in the widest sense, and advice from a variety of services, and financial support in various forms without means testing to priority groups such as the young, sick and elderly who are all, almost by definition, dependent (Gregg, 1973). Governments and political parties of whatever colour have not advocated a policy of withdrawing such support in the form of pensions from the elderly until very recent times. But from the public response in newspapers, and lobbying of MPs by pensioners and others, it looks unlikely that the present suggestions will be pursued. Such a view, however, still leaves the difficulty of how we give a suitable or proper degree of care while still adhering to the idea of independence.

The link between medicine and the elderly is increasing, if for no other reason than that life expectancy is rising accompanied by an increasing expectation of medicine being able to stave off the effects of ageing. Stearns (1977) comments that in the 19th century people rarely saw doctors unless they were rich or very poor and very ill, though the study of geriatrics arose then. He suggests three reasons for this:

"First, there wasn't much point going to doctors for they had little to offer, even though their knowledge expanded immensely. Second, the sources of improvement in the medical care of old people would commonly come outside geriatric medicine per se ... Third, at least until the late 1930's, the health of the elderly depended very little on the state of geriatric knowledge".

(p.81)

Geriatric medicine, though much more highly thought of now, still has a slightly "Cinderella" connotation about it. The weight of numbers, particularly of old ladies - at least in part a result of two world wars - has caused the medical profession, as well as society in general, to take the problems of the elderly seriously. This change has increasingly given the elderly themselves license to make decisions about their medical treatment. There are of course organisations like 'Help the Aged' and 'Age Concern' who are only too aware of the services, medical and others, which are not taken up by elderly people. Such a realisation is an indication of the lack of homogeneity of the elderly.

Another misapprehension is that the problems of the elderly occur only in the industrialised world. The reality is quite different, however, since wherever severe disablement, whether physical or mental, occurs, imbalance follows. Foner (1985) comments:

"In other societies, as in our own, serious imbalances of power, privilege and opportunities for independence and autonomy exist between the frail aged and their younger caretakers, and as a result, tensions are inherent in intergenerational relations in many different cultures".

(p.27)

The obvious point that the elderly who cannot earn their living by taking an active part in the production of food are inevitably at risk carries over from rural economies to urban ones. Some societies deal with such problems by abandoning or killing the elderly people concerned. There are other societies, though nomadic in lifestyle, who do provide care for their frail elderly relatives.

It is true that, though it is common for elderly people in our society to desire independence, other societies find it more acceptable for the frail elderly to receive care from children or other kin (Shelton, 1968) and thereby make the whole idea of dependence much more acceptable. Sidel and Sidel (1974), while looking at a different cultural background, make a similar point:

"Individuals never occupied the central position in China that it has in the West for the past several hundred years. In pre-revolutionary China the individual was seen as part of a group, part of his family, his clan, his village. His responsibilities to his living relatives and to his ancestors were clearly delineated and keenly felt ... To 'serve the people', to work for the good of society, is the prevailing ethic".

(p.23)

No matter how interesting it is to realise how other societies deal with their elderly members, it remains necessary to learn more about the reality of those older people who are cared for by nurses. In her survey of 'The Elderly at Home', Hunt (1978) points out that very many elderly people manage as well as people a great deal younger than themselves. Often the only help they require is in climbing step-ladders to change

light bulbs, take down curtains or to redecorate. If there are family members who visit often, or kindly neighbours who are trusted, or financial security, then such dependencies are not a great problem. While this is true, there is the reality of increasing incapacity as the result of illness and it is so that very many frail old people are maintained at home by means of the devoted permanent care of relatives (Charlesworth et al, 1984).

INDIVIDUALITY OF THE ELDERLY

Whatever the theories which explain ageing processes, or the influences exerted by society in general or health personnel in particular, perhaps the most important fact to remember is that the elderly are not a homogeneous group. There has been much prose written about the elderly by authors such as Taylor (1982) where she describes the life of an elderly lady who gives up her home and goes to live in an hotel. She also describes vividly in another book the ageing process in one of her most bizarre characters, suitably given the unlikely name of Angel, which adds to the reader's involvement and dislike (Taylor, 1984). Bailey (1982) also uses the plight of an elderly lady who is removed from home to a nursing home which she so dislikes that she "misbehaves" and is generally obstructive and unco-operative as a means of trying to get home again. The reader is left with a terrible scene in which release seems to have been given, along with the knowledge that the joy of release is about to be turned to depression and

anger when the nursing home is replaced by a more terrible prison.

Poets have also pointed out the reality of old age. Joseph (1973), for example, shows the expectation of her being able to be more like her real self when she is old. 'Katie' writes hauntingly about the reality of the frailty that age has brought and makes a plea to the nurses to recognise the real person within her and not to lump her with all the other patients in their care (Carver and Liddiard, 1978).

The whole genre of biography, autobiography and diaries demonstrates powerfully the consistency of the personality of individuals through their lives. Brittain (1978) in two volumes makes clear the influences which, though they were shared by many others, influenced the author idiosyncratically. Another slant is given by Stott (1985) where she makes clear what she thinks about and how she has reacted to incidents in very recent times as well as those in the past from her stance of advancing years. In the Hebblethwaite (1983) biography of Pope John XXIII, there is a nicely drawn figure of an elderly man who has a great destiny thrust upon him at an advanced age, and a clear picture from diaries and observations of him of what he did with that destiny in light of his character and past background. By collected biographies, Blyth (1979) shows another strand of individuality. Some experiences, such as marriage, bereavement, work and school, are shared by many. In the section concerned with war, entitled 'The Beloved Holocaust', Blyth records the quite individual reactions of

those who shared the same experience in the First World War which serves to demonstrate the separateness and individuality of people. On an entirely personal level, Newton (1980) gently tells through her diary how she felt personally about life in various nursing homes rather than trying to explain the feelings and views of those who shared her surroundings. Thus individuals, be it for reasons of personality or any other cause, will perceive and react in different ways to apparently similar situations.

From this review of ideas about ageing it can be seen that ageing happens to individuals individually. The next section, then, shows the relationship of ageing to autonomy.

AUTONOMY AND THE ELDERLY

OVERVIEW

In this third major section there will be discussion of the crises which occur with age and where autonomy is challenged. Risk is then discussed and how it can be responded to.

INTRODUCTION

In considering the concept of autonomy, the most important point which has been underlined is that it concerns making and carrying out decisions which are right for the individual in the sense that such decisions are consistent with the stance of the person. Though autonomy can be understood to obtain for most people, it has already been noted that there are a variety

of individuals for whom autonomy is not a real option. At the margins of life, that is to say the unborn and those who are unconscious, there is little option about what the patient can contribute to decision making in a direct way. With the increasing numbers of the elderly, the problems of autonomy will also grow. As has been pointed out previously, the elderly are not a cohesive group and, while there are some whose mental abilities call the possibility of independent decision making into question, there are many for whom no such problem exists. In some ways, it is becoming increasingly hard to decide which groups require decisions to be made for them for neither children nor the elderly achieve or lose ability uniformly. Too, some elderly people do not lose ability consistently.

CRISES

For the elderly person who is well and still living at home autonomy is accepted as a quite proper aspect of living and in all likelihood not much thought about, just as is so for much younger people. Problems only arise when there are big events which fundamentally affect the situation. These crises may be of long duration, like retirement, or short, like hospitalisation, and often it is their duration which has the potential to alter radically the exercise of autonomy.

Though a crisis has an inherent sense of danger, it also has the potential for positive outcomes. By its nature a crisis is sudden and therefore its outcome cannot be predicted. It can produce circumstances which provoke growth and development in

quite undreamt of directions. Retirement, for example, can be a beginning of new and interesting contacts, hobbies or community service, or just having time to know neighbours or grandchildren. The ideas of crisis are closely linked with risk, since risk is intrinsic to crisis. It is for this reason that discussion of risk follows in the next section.

Retirement

There are various crises which befall the elderly which make it harder for them to retain autonomy. Retirement is perhaps the largest and shared crisis which befalls this age group. The difference between those who have worked outwith the home and those who have not demonstrates this. Generally speaking, men who have worked full-time find retirement provides a lot of free time. Of course for many retirement marks the start of a new part of life, an opportunity to develop or indeed start new interests. On the other hand, for women particularly there may be no official retirement and indeed, for those who have been homemakers and wives, the changes at the age of 60 or 65 may be infinitesimal since these roles are continued. The main change may in fact be a curtailment of social activity resulting from the husband's increased presence in the house, especially if by inclination or habit he is not sociable. There is evidence which makes it clear that women are much less likely to get access to the services made available to men in similar circumstances (Charlesworth et al, 1984).

The social contact which accompanies work may diminish noticeably after retirement. Dependency may result in such a person being called to the attention of the health visitor or the district nurse. There are occasions when the real or immediate need is met by the professional's call. Acknowledgement of the fact, however, would mean that the isolated person's one caller, perhaps the only regular caller, would cease visiting. In such an instance the lack of acknowledgement might mean that it is the dependence which will maintain the contact.

Hospitalisation

Hospitalisation is the crisis which is potentially the most jeopardising to autonomy. There are many illnesses which will demand hospitalisation. For example, those which affect the urinary tract, digestive tract, or eyesight, which, although they do not affect mobility, do severely dent the patient's self-confidence. The dimension of self-confidence in getting to the toilet in time; or the problems of being offered food which is not suitable; or the fear and confusion of failing eyesight, lead to such sufferers becoming housebound. Other illnesses, for example, a stroke, which also necessitate hospital admission may easily turn into long-term incapacity in that mobility may well have to be surrendered permanently, which in turn may lead to long-term care. The reality of having to give up a home is one of the most awesome events that elderly people face, and it is full of risk for them.

Cormack (1985) noted that patients who have been institutionalised are characterised "by lack of initiative, apathy, lack of interest and submissiveness". For many of these patients almost all choice is removed as well as personality. Nurses tend to like compliant patients and those who are not co-operative are seen as being difficult (Stockwell, 1977). It is this awkwardness which may in fact reveal their autonomy. There is some evidence which demonstrates that how nurses treat patients and manage their work has influence on the degree to which patients become dependent (Miller, 1985).

It is the decline of mental powers and the onset of confusion and dementia which most older people fear, and carers find most difficult to cope with on a long-term basis (Sanford, 1975). These patients are among those which nurses refer to as being high-dependency. Of course this is not the high-dependency which makes great demands on staff numbers because of the sort of staff required to deal with high technology. Rather it is the demand of constant care and support which equally needs suitably trained staff. Sadly, the appeal of high technology is greater than that of needy people. It is this fact which makes demands of staff/patient ratios which can be difficult to answer (Stevens and Goucher, 1958; Wilkin and Jolley, 1979).

Poverty

Finance, or its lack, is a difficulty for many elderly people. Very many are on fixed incomes and, though there is a state pension, the sum it provides is not princely. Poverty is

an important element in the lives of all those who suffer it, but the elderly suffer grievously (Townsend, 1979). As Johnson (1982) notes:

"In the absence of a shift in the political economy of old age in Britain the prognosis for the active and the dependent person is one of continuing restriction and subjection to professional paternalism - perhaps increasingly shared with the new paternalism of volunteer help". (p.155)

From their position of commitment and expertise a group of professionals, in response to the 1979 Royal Commission's Report on the National Health Service which took "a fairly narrow 'health service' view", put together a series of articles entitled 'The Impending Crises of Old Age: A challenge to ingenuity' (Shegog, 1981). After coming to 46 specific conclusions the group finally made a general observation that "it is political will married to administrative action to reallocate existing resources which is required" to aid the elderly. How individuals can in fact provoke such change is a moot point and this is not the place to make suggestions in that direction. Though recognising that there are cultural, political and social differences between countries, the problems faced in Scotland when contemplating care of the elderly are shared, if not exactly, at least in some measure by other countries. A World Health Organization survey (Heikkinen et al, 1983) describes the similarities in Europe which are shared, not surprisingly, with American data (Shanas and Maddox, 1976). In 1983 a report on long-term care for the elderly was published by the United States Department of Health

and Human Services as part of the continuing attempt to resolve some apparently intransigent problems such as housing for the frail, medical care and lack of income (Vogel and Palmer, 1983).

RISK

The idea of crisis raises the concept of risk and this is an integral component of autonomy. Social work is much more aware of the idea of risk and is much more prepared to enunciate it (Brearly et al, 1980). This is not surprising since the main thrust of social work philosophy is attempting to allow clients to retain as much decision-making as possible. Since the traditional nurse's view of patients has been one of dependence, the essential ethos of nursing has been of caring by doing things for people and therefore inherently risk is removed. In the study from which some of the impetus for the present study comes, nurses spoke of the need to make sure that risk was diminished, if not prevented altogether (Melia and Macmillan, 1983). Perhaps the time has come to challenge that. If we are to encourage people to take responsibility for their health, then we must be more prepared to encourage risk taking. Johnson (1976) suggested that the elderly are entitled to select their own destiny within given limits. Part of nursing's problem as far as care for patients is concerned is that there are no agreed 'given limits'.

The conviction that nurses must allow patients freedom to make decisions and then act upon those decisions, even when the

patient does not have the physical freedom of action, is inherent in this work. Of course there are many elderly people who have freedom both to make decisions and to carry them out. Most of those with freedom of action do not fall within the scope of nursing, even in the community services. Where difficulties arise are inevitably in the 'grey areas' of whether the patient's freedom of action is real or not. What makes such areas 'grey' is risk. There are elderly people who are rather unsteady on their feet. If such a patient goes into hospital because of, say, a chest infection, he might be totally sure that for him there is no question that he will return home. The inherent risk of injury resulting from a fall may be real enough. Such a risk, however, is a fact of life and if the chest infection had not brought such a patient to professional notice the risk would have been tolerated without question. The professional involvement changes things radically in that the nurses, as well as doctors and others, do feel that risk must be diminished to the point of non-existence. But that, in part, is a means of self-protection on the professionals' part against charges of negligence from relatives or society at large. Though long-term care or 'Part 4 accommodation' (Social Work, Scotland, Act, 1968) might seem to provide a secure environment, it remains so that the unsteady person may still fall but the rationalisation that "at least we did all we could" would seem to explain away the risk.

Recently it was reported (Scotsman, 1985) that a lady in her eighties, who had been a widow for a number of years, had

moved out of her house and had been living in a wardrobe in a garden shed. The local authority took legal measures to have her admitted to hospital compulsorily to protect her from hypothermia. This is another example of society not being prepared to accept the risk which clearly the lady was choosing for herself. Though cold can be expected in the winter, there is no reason to suppose that one winter is going to be worse than another; nor indeed any evidence that the local authority will allow her to leave hospital in the summer. Although one could reasonably claim that it was eccentric of the woman to prefer the wardrobe to her house, there is no evidence that she was incapable of making decisions for herself that seemed right to her. There is no suggestion either that the way she had been living was an inherent danger to anyone else. A strong argument can be put that even in this example the risk ought to have been taken to allow the lady to live as seemed right to her.

Though some of the examples of dependence given will also result in apparent loss of autonomy, the need for dependence on others should not automatically deny the individual's right to be given the chance to exercise autonomy. While, if after a fall, traction is required, there will be a considerable degree of dependence with activities of living because of enforced immobilisation, there is no need at all to relinquish how one is addressed, or what one wears, or what one eats, or what time one goes to sleep, or which visitors one receives, or many other decisions of a day-to-day nature. If it becomes clear that the probability of returning home is remote, then the

patient ought to be fully aware of such a probability from the earliest possible time and be a full participating member in any decision making process.

Such a conviction has implications both for nurses and patients. Nurses and others must learn to accept risk, and patients and relatives must learn to accept responsibility. It will be demanding of time and energy for staff, though rewarding, since taking people seriously always is (Long and Proffit, 1981).

Dealing with Risk

Learning how much risk one is prepared to cope with, either as an individual or on behalf of others, can only be achieved in community in exposure to a variety of people. Klinefelter (1984) states:

"... what Jung and Erickson have isolated is one of the primary tasks of every stage of adulthood, especially in the second half of life, namely, the discovery or rediscovery of the reality and power of one's inner or spiritual world ... The view that I have tried to put forward is that successful ageing ... is a function of the individual-in-community, and is a genuine possibility for a great many people who have prematurely and mistakenly resigned themselves to something less". (pp.17-18)

To learn acceptance of risk or responsibility calls for courage. Part of the success of courage is having dealt with anxiety, which is intrinsic to the thinking needed, and listening to others before courage can be exercised.

Smail (1984) examines the meaning of anxiety in 'Illusion and Reality'. While he accepts that anxiety is both good and bad, he levels the charge that those who have care of

handicapped people, often from their own very good motives, do not take seriously the lessons that the patients have learned from life and thereby diminish the contribution that they have to make. To change this and start accepting the risk of patient's knowledge and choices is to demand courage on the part of both the participants in such a relationship.

Ultimately, what is most required now of the elderly if they are to retain autonomy is courage. It takes courage to be an individual and to maintain distinctive qualities. It takes courage to go on making choices. It takes courage to reiterate to each new member of staff who comes to a ward what is seen by the elderly person to be right for him. It takes courage to be difficult and it is often only by being difficult that one's view is listened to. It takes courage to discover or re-discover the "reality of one's inner world". Reiteration and discovery or re-discovery, as well as an ability to be difficult, not only takes courage but energy too. Nurses need the courage to make a high priority of spending time talking to patients. Also they need courage to take patients seriously and take risks in acceding to patients' choices, and helping relatives or society to take responsibility which hard choices demand.

Tillich (1952) explored, in a series of lectures about courage, the ideas of being and anxiety and faith. The challenge that is extended on what people think they are and the relationship of their being to God or the "depth of reality" in face of complete doubt he saw as being a matter of courage. He ends his argument by claiming:

"The courage to take the anxiety of meaningless upon oneself is the boundary line up to which the courage to be can go ... The courage to be is rooted in the God who appears when God has disappeared in the anxiety of doubt". (p.183)

This means that both Smail and Tillich suggest, if differently, that courage is not something that can be achieved alone. Rather it is only possible in community with other people.

From this review of the literature on the elderly it can be seen that self-determination is important for everyone. The importance of being in control of one's life does not diminish with the advance of years. The various theories about ageing underline the vulnerability of the elderly. This vulnerability has provoked the further definition of autonomy.

DIMENSIONS OF AUTONOMY

OVERVIEW

The first aim of this study was to analyse definitions of autonomy. A review of the literature on that subject, as well as related concepts like freedom and paternalism, lead to the conclusion that there are three dimensions which seem to characterise the various nuances. These dimensions are autonomy of action, autonomy of will and autonomy of thought. While these three strands have been seen as being important by different people at different times the interrelationship between them has not been made clear. While consideration of their exercise has been important, not least in a nursing

context, most of that consideration has been from the professional's point of view. If one wishes to turn that consideration on its head and look at it from the patient's stance, then the actual relationship and process needs to be looked at. Therefore the relationship of these dimensions was explored and there will be some discussion of the possible factors which interfere with an individual's ability to exercise autonomy to the full in any of its dimensions.

INTRODUCTION

The concept of autonomy concerns an individual's ability to think about and decide on something freely, and to act in the light of such decision and thought. Clearly, then, there is an interdependence between the mental part of the process of self-determination and the physical outcome or response. It is being suggested here that there is not only a simple relationship between the three dimensions, but in fact it is an hierarchical one. The separation within the mental part is important since it clarifies two distinct parts, namely autonomy of thought and autonomy of will, or intention as Gillon (1985) terms it.

It is of importance to examine these relationships since they operate where ordinary people make up their minds about ordinary things. Such decision making goes on all the time. Patients are accustomed to make up their minds, as are relatives or lay carers, and in this regard the professionals, whether doctors or nurses, are no different. It is because one does it all the time that one is largely unaware of it.

In the practice of nursing, however, there seems to be an added importance to discern these relationships since there are many members of the public, as well as some nurses, who are aware that respect for autonomy is not what it might be. They see a large amount of interference with, or overriding of, or ignoring of the choice of individuals which is often the response to lack of knowledge or lack of confidence rather than wilful unkindness. Another worrying aspect of why people do not give full rein to the wishes of patients is that a great deal of nursing is learnt not formally but by "sitting by Nellie", and there are many role models who pay little or no attention to autonomy, its preservation or encouragement. This holds good not only for nurses but for doctors as well. It is suggested that with the explanation of dimensions of autonomy, nurses can begin to understand the need to consider autonomy and to do something practical about righting the situation of its being ignored. The hierarchy will represent the notion that there must be autonomy of thought before there can be autonomy of will and that these, in the presence of physical ability, will be required before autonomy of action can be facilitated.

AUTONOMY OF THOUGHT

There is no dubiety that thinking is an intrinsic component and indeed the basis for the exercise of autonomy. In writing about autonomy there has been constant reference to reasoning; mental ability; deliberative stretching out; and rationality or other such ideas, which of course are all in the

realm of the mind. Autonomy of thought is the name given to that dimension which includes having views about and preferences for things, holding moral stances, and making decisions. These are aspects generally referred to as "thinking for oneself" or deliberating about things. Another prerequisite is knowledge and this is one important aspect of the deliberative process which, in people in hospital or being faced with illness in themselves or others, is most likely to be at fault. We think about major issues like abortion, banning the bomb or caring for the elderly, and about small issues such as is chocolate good for us, would that pink dress suit me, or will I go to bed now. These are all matters which we are free to think about, deliberate about, consider the possible arguments, and decide about, but importantly with no absolute intention of acting or willing to act upon the deliberation. Though of course they might well display a consistency of character and moral stance.

Such examples suggest that we cannot act without thought. Some, however, might claim that there are many activities which we undertake without thought. These seem to be of two sorts; first, there are voluntary actions like scratching an itchy spot. The fact that the thinking step happens so quickly that we do not really notice it, possibly because the steps have been done so often, does not mean that thought has not been carried out, or it is possible to rationalise about the matter. Not scratching when the itchy spot is in some part of the anatomy which socially precludes liberty to scratch

demonstrates thought. Secondly, there are involuntary actions like the knee jerking when it is struck in a particular place, or blinking the eyes when something touches the eyeball, or sneezing. These responses have a different physiological explanation, though it may be possible to overcome such responses by sufficient thought and will.

Thus it seems that thought is the prerequisite of all autonomy, as without thought there can be no autonomy. If such a state of no thought or no evidence of thought exists, as in the infant, the unconscious, the profoundly ill, the deeply drugged, or in extreme instances of mental disturbance or disability, then personal autonomy is absent. In such instances obviously other means must be sought and found to make right and proper decisions for or on behalf of the individual, and here the nurse has a proper, if difficult, role.

In one sense these situations are easy to deal with, in that there is little or no doubt as to what the state is and what the appropriate action will be. It is much more difficult when there is lack of agreement among the carers, either professional or lay, as to whether the person is thinking clearly and one can argue for a long time as to whether a person is thinking rationally. It can be tempting to assume that a person whose decision is different from one's own is showing faulty thinking. There are occasions when, in fact, there is thinking going on but the communication of that is difficult, if not impossible. How, for example, do we deal with a patient suffering the after-effects of a stroke who cannot

speak properly? The temptation to take over decision making is profound, not on the basis of the patient's lack of physical ability but on the assumption that if he cannot speak he probably cannot think. It is one of the very worrying aspects of care within psychiatric and mental handicap hospitals. Here there are patients who are articulate and express will, but the impression prevails that because they are in a hospital with that sort of illness it must necessarily mean that they cannot be thinking rationally (Rodenbach, 1982).

AUTONOMY OF WILL

The second dimension of autonomy is autonomy of will. This is the bridge between thought and action. It is the ability to decide to do things on the basis of thinking. This stage cannot occur without thought and, without it, action cannot happen. It is perhaps the area most inaccessible to the observer, since the deliberative process is for most people an internalised one. But, by contrast, this second step is often verbalised, as in "I must put the kettle on"; "I will not take part in terminations"; or "I must speak to the child". The idea of will-power perhaps helps to elucidate the nuances of control of actions. It is possible to decide not to eat a second chocolate, despite its being available and the individual being extremely fond of chocolate in any form. All these examples show the relationship between thought and action, and give some indications as to the feeling that there are degrees of will and, the converse of that, that there can be limitations of it.

This dimension is the most vulnerable of the three. It is open to interference by many pressures. These include duress in getting patients to comply with involvement in research trials that they do not understand and do not really want to participate in but do so in case it jeopardises their treatment. But, in the present context, interference can be imposed by drugs, stress, illness, social conditions, unemployment, or ageing per se, as well as psychiatric disorders. Mood may also impair autonomy of will. Personal factors can reduce the will to finish or even begin a task. This sort of reaction may be experienced by patients when a nurse, or other carer, says something which demolishes the confidence of the patient. It might not only be the patient's reaction but the nurse's mood which is transmitted to the patient and thereby depresses the patient severely. When individuals are affected by such impairments the temptation to override those aspects of autonomy which remain extant may be overwhelming. Such lack of autonomy, or interference with it, tends to provoke irritation in those near or caring for the afflicted individual. The problem of working out what the difficulty is requires time and care, as well as patience, and of course taking over the decision making is an easy and tempting solution.

AUTONOMY OF ACTION

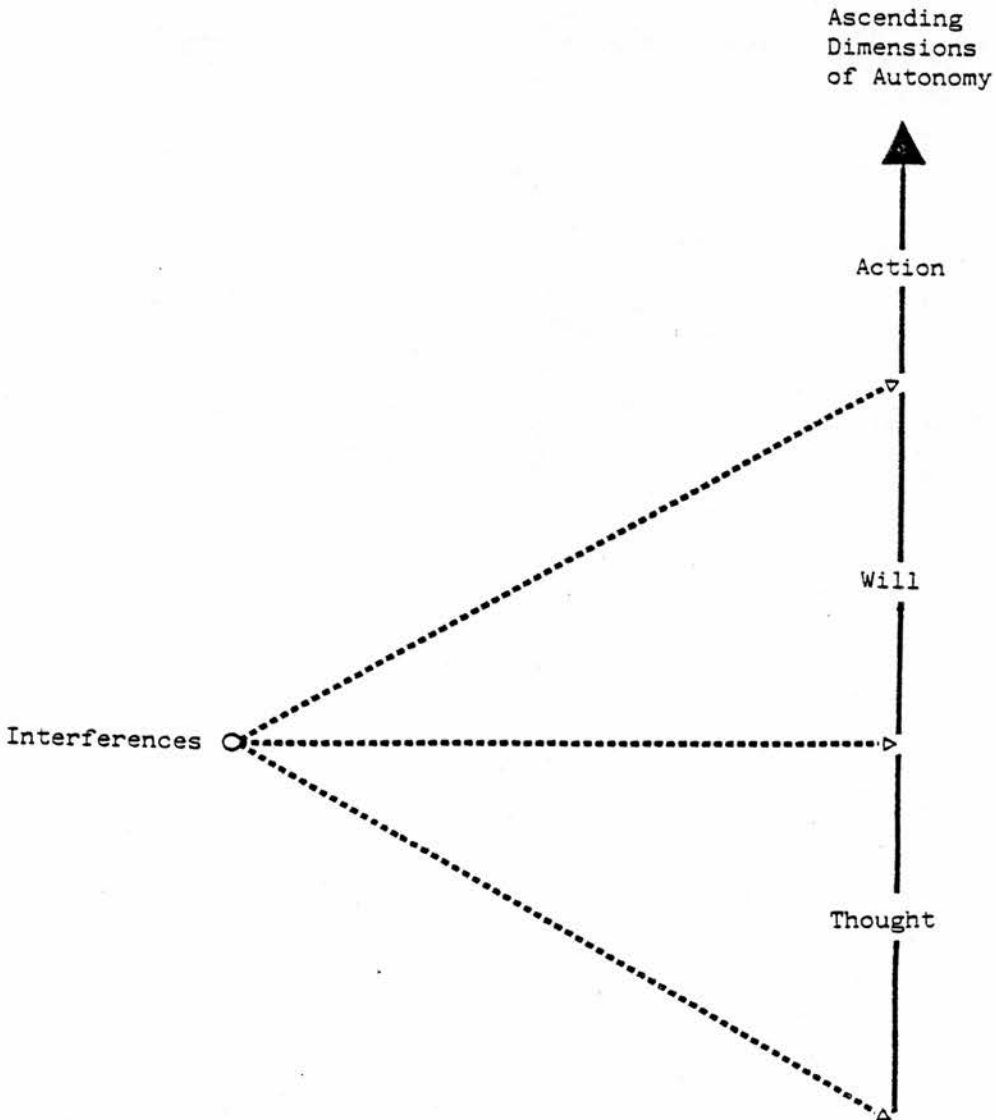
The continuing development of the model extracted the final dimension, that of autonomy of action. Autonomy of action is the ability and freedom to act on the basis of will and thought. Therefore to have action there must be thought which, in turn, produces will which is the necessary precursor of action. It is possible to be unable to move, say suffering from a spinal injury which leaves one paralysed from the neck down, and therefore quite incapable of autonomy of action but to have retained without any impairment autonomy of thought and will. Such a situation is exemplified by Clark (1978) in his play, 'Whose life is it anyway?'.

This is the dimension of autonomy which it is most difficult to deny, particularly if the individual is articulate. Of course, this does not mean that all members of society remember. The complaints of physically handicapped people confined to wheelchairs being treated as if they are children at best, or stupid at worst - the "Does he take sugar?" syndrome - bear witness to this. On a more common level, the abilities of those suffering from arthritis who still do all the things that they want to do are an encouraging reminder that thought and will can be turned to action despite difficulties.

Figure 3 shows the author's model of the dimensions of autonomy. The three dimensions of autonomy of thought, will and action appear in ascending order. Also shown are the possible points of interference with the different dimensions. Such

interferences, when they occur, affect the hierarchical relationship of the dimensions. This means that when an interference affects autonomy of thought then the hierarchical relationship of autonomy of will and action will probably fail altogether or, at best, be affected. When the dimension of autonomy of will is interfered with then autonomy of action will be affected. If the interference affects only autonomy of action then autonomy of will and thought will not be affected.

FIGURE 3: Dimensions of autonomy and possible points of interference



HIERARCHY AND RELATIONSHIP

It has been shown in the author's model that there is a hierarchical relationship among the three dimensions. Autonomy of thought is the fundamental basis where attention to the exercise of the individual choice is easiest to ignore. Next there is autonomy of will in the hierarchy where it is more difficult to ignore personal decisions, but where it is most vulnerable. Finally, there is autonomy of action where it is hardest to deny the individual's wishes but sometimes easiest to override them, such as by the creation of dependence with nurses or carers doing everything for the patient. The other point to be underlined is that without thought there can be no autonomy of will and therefore no autonomy of action. But it is possible to have limited autonomy of will, and therefore limited autonomy of action, while retaining autonomy of thought. It is also possible to have limited, or indeed an absence of, autonomy of action while retaining autonomy of will and thought.

Autonomy can be seen at one level to be about independence. To some extent this is proper and yet it is not totally satisfactory. The continuum of dependence to independence is generally accepted to be concerned with physical ability or inability. It is on this premise that staff ratios are established in the United Kingdom. It is very tempting to see autonomy coinciding completely with dependence to independence, or even working in parallel, but since it is possible to be totally physically dependent and yet retain

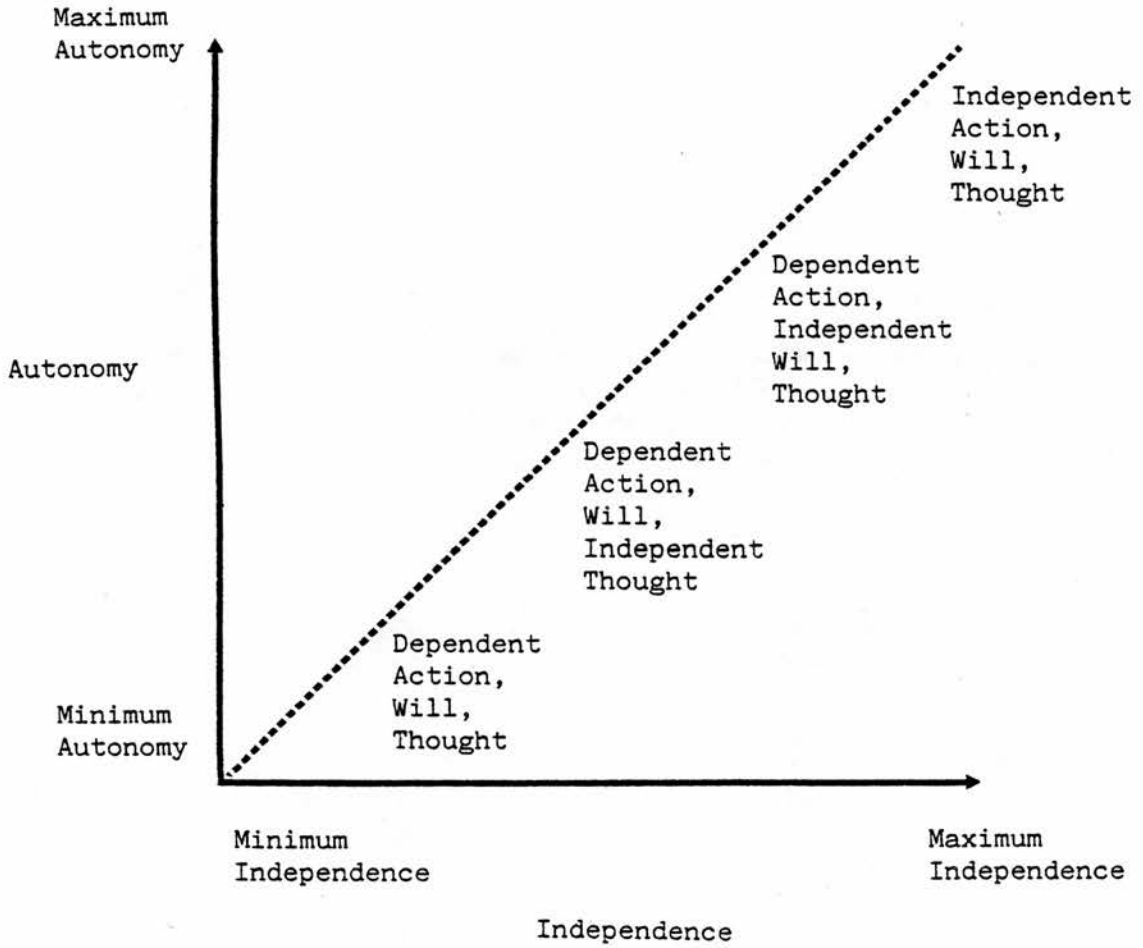
autonomy of will and thought it would seem that, in fact, the two concepts are better seen in a diagram indicating bisecting continua.

IMPEDIMENTS TO AUTONOMY

Figure 4 shows a graph with the vertical axis indicating autonomy, while the horizontal axis indicates independence. On the X-Y line there are points indicating the relationship between autonomy and independence when there are varying degrees of interference of autonomy of thought, will and action.

Autonomy has, in the author's model, been described as having three dimensions, namely thought, will and action. Autonomy of thought is the basic one and on it the other two depend, for without autonomy of thought there can be no autonomy of will, and without will there can be no autonomy of action. Interferences can occur at any point in the hierarchy. These interferences, such as drugs or illness resulting in profound pain, anxiety or unconsciousness, would each interfere with, if not prohibit altogether, autonomy of thought. If there is autonomy of thought but an interference, such as fear, tiredness, or not being able to come to a resolution of the thinking process, then there will be an interference with autonomy of will. It is this dimension which is most vulnerable to influences outwith the individual; for example, adults or professionals can intrude and take over the decision making and

FIGURE 4: The relationship between autonomy and independence



deny or doubt what the person has decided for himself. The third dimension of autonomy of action, which rests on autonomy of thought and will, can be interfered with too. At this point the interference is most likely to be of a physical nature; for example, one might, as the result of physical disablement, be confined to a wheelchair or bed. Also, some old people are confined to wards or their houses and so depend on other people to carry out their wishes.

Though there is a certain satisfaction to be gained from having devised a theoretical model, that is not sufficient. Before any claims can be made on its behalf there is a need to ascertain that it is applicable in the real world. For this reason the life histories were subjected to analysis using the model. This stage of the work will be discussed in the next two chapters.

CHAPTER 3

Research Method

OVERVIEW

In this section the life history method is discussed. An explanation is offered for the choice of this method to elicit information about autonomy from a group of elderly people. The means of recruiting the group and the conduct of the interviews are recounted. Some ethical considerations raised by pursuit of research using elderly participants as well as the life history method are discussed.

METHODOLOGICAL ISSUES

Hill in 'On the Relevance of Methodology' claims:

"Criticism of methodological practice is not a new parlour game but a well established form of professional recreation. Two types of response to such criticism continue to be typical of the devotee of standard methodological practice. We either ignore such nonsense, or if we notice it at all, we dismiss it with arrogant disdain. Thus, Sorokin's attack on the 'psychological disciplines' and their methodology was labeled 'rather demagogic than scholarly', and large portions of the ethnomethodological approach of Garfinkel were categorized as being either 'trivial' or a 'major disaster'".

(Denzin, 1978, p.47)

This illustrates the debate as to the best method of collecting data; a debate which is sometimes characterised by dogmatic assertions that only one method is appropriate or right. The debate ought much more to centre on its relevance to the study of particular topics and the rigour with which any method is pursued. Of course there are some researchers who have a natural aptitude or flair for either quantitative or

qualitative methods. Such gifts may be a determining factor in the sort of research undertaken or areas explored and to claim for such work an aura of inherent value seems inappropriate. Despite personal predilections to particular modes of work, the ultimate factor in selecting the method must be the research topic. Before continuing with the selection of a particular method there is perhaps need to set it within the context of the sorts of approach which have been used and are still being used.

Most writers of textbooks on research methods have written about the issues paradigmatically. Generally, these paradigms are labelled as either positivism which underpins quantitative methods or, on the other hand, naturalism which explains qualitative methods, ethnography in particular. Some have, of course, found neither paradigm entirely adequate (Hammersley and Atkinson, 1983; Denzin, 1970; Bulmer, 1984).

Positivism

Comte is the philosopher who is most commonly deemed to have devised the philosophical system which is covered with the label of positive philosophy. The foundation of the system is the belief that man can have no knowledge of anything except phenomena and that the knowledge of phenomena is relative rather than absolute. During this century there has been a development called 'logical positivism' which is concerned with determining whether or not statements are meaningful (Kolakowski, 1972).

This manner of examining the world has had great influence on social scientists and has encouraged the status of experimental and survey research, and the means of analysis associated with them. There are many strands in any system of thought which are involved when that system is applied in a variety of settings and over a period of years the emphasis is bound to change. There are probably three main strands to positivism which may be differently weighted but seem to be basic (Bryant, 1985). The first of these, the logic of experiment, which is the basis of physical science, has been seen as the model for social research. It is in the experiment that quantitatively measured variables are manipulated to identify the relationships between them. Many claim that this is in fact the defining feature of science.

The second strand is the idea of universal laws. The argument is that there are regular relationships which hold in all circumstances. One can demonstrate the statistical version of this only where there is a high probability of these regular relationships applying across all circumstances since one does not count each one and examine the relationships. It is because of the emphasis laid on the need for generalisability of findings that social scientists lay great store by sampling procedures.

Third is the idea that what is observable is most valuable. This allows for repeated tests whose results, since they include no theoretical assumptions, it is reasonable to accept. All observers must be able to agree standard results.

The difficulty of achieving this in the social world has led to great emphasis on standardisation of procedures of observation to facilitate the achievement of measures that are stable across observers (Moser and Kalton, 1971; Oppenheim, 1966).

Naturalism

It was a reaction against these ideas that gave rise to naturalism. The main point of this view is that the social world must be studied in its natural state undisturbed by the researcher. Sensitivity to the setting where the research is to be carried out as well as an appreciation of the social world are of prime importance. The view is that human activity is affected by 'social meanings', that is to say the beliefs, motives, attitudes and intentions which surround and indeed suffuse all activity. Reality is seen by different people differently but each person needs to impose order or explanation on the world which incorporate his perceptions, values and beliefs. This has been called the 'assumptive world'. Young and Mills (1980) have noted the complication of the 'assumptive world':

"The assumptive world has a complex, but well defined and integrated structure within which four elements may be distinguished. First is the cognitive element, a man's ability to recognise the facticity of his world. The second is the affective element, encompassing a man's valuation of aspects of his world as he apprehends it. Third is the cathetic (sic) element which refers to a man's sense of relatedness to the world which he both creates and experiences. Fourth there is the directive element, wherein a man is moved to act upon the world". (p.6)

The function, then, of the researcher is to reveal the nature of the 'world'. There are those who say that this can best be done by observation from the outside, and conversely there are others like anthropologists who are of the view that such revelation can only be done from the inside. The idea that the researcher might be truly neutral and incorruptible, though held by many, is naive indeed. This leaves another option, that of the actively participating researcher. The participation is needed to enable the researcher to make correct interpretations of what data are being collected, and to elucidate and reveal patterns and meanings in them while analysis is being carried out.

Reflexivity

Garfinkel's (1967) concept of reflexivity is an important one for it makes possible the role of the participating researcher. The idea is that people are constantly seeing the world through their own eyes as well as from the perspective of other people, and indeed it is the active co-operating with others which creates and maintains the world. It is impossible to be a passive recipient of the features of an independently existing world. Denzin (1978), although claiming not to "have a strong grasp of the concept", speaks of the intuition needed to analyse the world in which we live or which we wish to explain. Hammersley and Atkinson (1983) were dissatisfied with naturalism and it is some grasp of the idea of reflexivity which has enabled them to make progress in the explanation of ethnography and its methods.

As has already been noted, the particular research topic is the fundamental factor in choosing a research approach. Autonomy as a philosophical concept does not lend itself to objective measurement. The experience and examples of autonomy are subjective. What one nurse would describe as an autonomous gentleman, another would describe as being a cantankerous old man. Since it is impossible to measure autonomy the world of positivism had to be rejected. The aim of the study was to identify examples of autonomy and therefore a naturalistic approach which allowed for reflexivity was adopted.

Interviews

A concept is not amenable to observation unless a clear definition can be agreed. Different writers have noted and laid stress on various nuances and facets of the concept of autonomy which meant that the main defining quality had initially to be sought. In this study people making decisions for and about themselves has been used as the basic defining quality. Such an idea is not possible to reach by observation. There would be a problem if such a possibility were real in that the researcher would have to be present when decisions were being made. The researcher would be left making assumptions that decisions had been made which might or might not be accurate; therefore interviewing seemed the only sensible method to choose. Talking about a difficult idea such as choice led to demand for reflexivity in the method. The interviews would have to be very flexible so that there would be times when direct questions could be put but also opportunity for non-directive interventions (Hammersley and Atkinson, 1983). Such interviews

are close to conversations in that normal conversation is generally a mixture of non-directive interjections along with some direct questions which each, but differently, advance the communication (Denzin, 1978). Goffman (1967) argues that when people are together there is an obligation to demonstrate a sense of involvement in the task in hand. This is another aspect of reflexivity which was used.

Life History Interviews

The decision to interview was not difficult but what sort of interview and how many was more difficult. Benney and Hughes comment that interviews are of many kinds, some of the:

"... standardised and so formulated (sort) that they can be 'administered' to large groups of people. This can be done only among large homogenous populations not so unlike the investigator himself in culture".

(Denzin, 1978, p.175)

The belief that the elderly are not a homogeneous group and that the experience of autonomy is quite idiosyncratic led to the rejection of the notion of using a fixed interview. Since one of the aims of the study was to find manifestations of autonomy over time the most appropriate method was seen to be the life history.

On a quite different level, if nurses are to make use of the findings of this study the method they use must be one readily available to them. When patients are admitted to hospital a series of case histories is elicited by, for example, both nurses and doctors but possibly also by social workers and physiotherapists.

Oral History and Biographies

The tradition of collecting oral histories from ordinary people where the important aspect is the eye-witness account has been a long one (Morrissey, 1980). Bede (673-735) makes it very clear that he used such accounts, as well as any documents available to him, in the introduction to his 'History of the English Church and People' (Bede, 1968). Such work has continued down the centuries. There are many organisations like the School of Scottish Studies in the University of Edinburgh along with the BBC which are influential and currently active in such work at the present time. Seldon and Pappworth (1983) have done work not only with ordinary people but also with what they call the "elite", by which they mean eminent in their field. Thompson (1978) has made a cogent argument and defence of such work. In his immensely useful textbook he claims:

"It (oral history) can be used to change the focus of history itself, and opens up new areas of inquiry; it can break down barriers between teachers and students, between generations, between educational institutions and the world outside; and in writing history - whether in books, or museums, or radio and film - it can give back to the people who made and experienced history, through their own words, a central place". (p.2)

Indeed there are many schools who have pupils go out to elderly people's houses or lunch clubs, or have elderly people come into schools and talk of bygone days. Such reminiscence has proved most stimulating on various levels, not least for the old people themselves.

Many people, nurses amongst them, have come to realise that reminiscence is of positive help to the elderly. 'Reminiscence Work with Older People in Scotland' (Development Advisory Resource Group and Extra Mural Studies, 1983), the proceedings of a conference, demonstrate very clearly the value that reminiscence can be to elderly people in the community. Nurses have also used the method to establish measures of patterning, or rhythmic repetition of events within the life cycle, and thus attempt to promote life satisfaction and indeed good health (Bramwell, 1984). Johnson (1976) has claimed that it is only by use of biographies that issues like dependency and independency will be seen in their full and proper context. It was therefore seen as being not only useful for the researcher to use the life history method but also for the elderly people involved in the study. Using a life history approach has the inherent possibility of being of benefit on two time scales. In the short term reward is derived by virtue of the research having taken place at all, thus allowing the participant to remember incidents not normally called to mind. In the longer term benefit will be afforded when the findings are used.

It is this method of life history which has been integral to the psychiatrist's work. Freud's (1909a; 1909b) work on paranoia and phobia are possibly best known. Various anthropologists interested in cultural psychiatry or the whole area of mental illness and its treatment as Langness (1965) and Creponzano (1977) are examples of such work. A related field is

that of psycho-history where the life story of an historic figure is treated to intense retrospective scrutiny and explanations posited for actions or theories which are demonstrated and can then be used as a framework for further study. Erikson (1975) has largely pioneered such work with studies of Gandhi and Luther.

The desire to explain why people do things and the influence of such decisions has long been with us, though the form has been generally in a literary one rather than psychological. One of the most famous biographies must be Boswell's 'Life of Johnson' first published in 1791 (1904).

Others have apparently had a desire to order, or perhaps explain to themselves, their actions and so have kept diaries. Pepys (Letham, 1983; 1985) is a good example of one who put his daily doings within the context of social, political and literary events of his time. It is interesting that a new edition running to ten volumes, as well as a shortened one volume edition, have been published in the last three years. These genres of biographies and diaries have been much used by historians as well as letters, another often used primary source. Letters, as in St. Clare Byrne's (1983) lifework on the Lisle family letters, have provided information; journalists, as Pizzey (1979) on battered women; as well as sociologists like Roth (1963) who wrote of his own experiences as well as that of others who shared his hospital ward, are examples of those who used such forms to explain the structuring of other people's lives. Lewis (1961; 1975) made his name by collecting

life histories, mainly in Mexico, and by using the original text allowed people of a quite different culture and educational background to learn about the realities of poverty.

Mead (1975) claims that:

"He (Lewis) was the first anthropologist to insist that there was a culture of poverty which deserved careful ethnographic study, and he invented the method of seeing individuals as they presented themselves within families, which were also placed within specific milieux". (p.vii)

One of the aspects of this work was that it caught and transmitted the lives and views of the illiterate. If someone had not taken oral biographies then such information would not have been available to the enormous numbers of people who have been made aware of intense poverty and its implications.

The use of biographies by sociologists has a considerable tradition with its origins probably lying in Poland. Znaniecki organised a competition amongst workers in Poznan during 1921. The results were recorded by Thomas and Znaniecki (1927) under the title 'The Polish Peasant in Europe and America'. The process of collecting 'pamientniki', that is to say written autobiographies, often of a topical nature, was continued by Cholasinski. This work of analysing sets of autobiographies has resulted in several examples of descriptions of the formation and transformations of social classes in Poland. These data were collected by running a series of competitions, some of which resulted in as many as 5,475 life histories being entered (Cholasinski, 1981)!

LIFE HISTORY METHOD

The term 'life history' arose, according to Langness (1965), because of anthropologists collecting life stories, by which they meant oral accounts of a person's life which were amplified by evidence from other people. These were therefore subsumed under the more general title of life history. Not only anthropologists but also sociologists used the same terminology (Langness and Frank, 1981). Based on the work of Allport (1942), Denzin (1978) points out that three basic forms of life histories are distinguishable. Firstly, the complete life history which covers all the subject's life. The data are presented in a first person narrative form but alongside this will be information gleaned from a variety of other sources and probably followed by an interpretation of the data. What one has at the end is a carefully documented life story of a single person, organisation or group.

The second form of life history is a topical life history. This shares the characteristics of the complete form except that it covers only one aspect or phase of an individual's story. Here there is much less weight or even no use of other sources of information. This is the category into which work on career patterns would fall. The term 'career', of course, has been used in the everyday sense of looking at work patterns as in the work of Bernard (1964) on women academics and Hardy (1983) on senior women nurses. There is another use of careers pertinent to the present study, namely that of life career, which has been used as the explanation of ageing. Such work is

represented by the Myerhoff and Simic (1978) collection of studies.

The third form is the edited life history, which may be either complete or topical, but relies heavily on comments, explanations and questions of the researcher to elucidate the theory of hypotheses. There are many sources from which data can be collected; other closely involved individuals are perhaps the most commonly available and used. The other sources are such archives as census material, church records, police reports, government papers, works of fiction, newspapers and magazines as well as photographs and film material. Another group of archive material is composed of private papers, which include autobiographies which can fall into the same category as life histories. Diaries, letters, business accounts, interview documents or questionnaires, account books, journals which, unlike diaries, are not generally kept daily, provide different examples. All these secondary sources have been used to check the veracity of the account and are therefore seen as being very important indeed. Denzin (1978) goes further and advocates using a combination of methods which he refers to as "triangulation".

In the current study there is no need to demonstrate historical veracity. Therefore the second form, that is to say a topical life history, was the method used which looked specifically at one aspect of the individual's life, namely how decisions were made. It was felt not to be of great importance to ascertain that a particular decision had in fact been reached or that it had been reached in a particular way.

PROBLEMS OF THE METHOD

Bertaux (1981) makes an interesting observation about the recording of life histories:

"It seems to me that the invention of the tape-recorder modified in a subtle but substantial way, the life story as a form of data. Instead of taking notes, research workers could now record series of life-story interviews. Anthropologists did so extensively: some of them worked on the data thus collected and published it as autobiographies (Lewis, 1961; 1964). Although they read as first person accounts, these texts had in fact not one author but two; the narrator himself, and the research worker (Catani, 1975)". (p.8)

Indeed this might well be so but since such machines as tape recorders do exist it is almost beyond reason to prohibit their use. However, that does not diminish the responsibility to make clear when writing up such data what was original from the respondent and what came from the researcher.

Among the detractors of the life history method, there are those who have difficulties in accepting the relevance or value of single case studies. Some researchers have found that life histories can be well used to generate hypotheses in an unresearched area, though these researchers would wish then to move to a positivist stance and eventually test the hypotheses and subsequently incorporate them into theory. Although life histories can be used in this way, generalisability remains a problem. Halfpenny (1979) has summed it up by saying:

"Comparative statistical studies generate only hypotheses suggesting that the many units studied share some of the same properties, whereas case studies have the advantage that they permit researchers to

hypothesize generalizations about the structural relations between different properties of the one case and between properties of the case and properties of its context". (p.10)

STRENGTHS OF THE METHOD

Faraday and Plummer (1979) claim that life histories can grapple with three problems:

- "(1) the subjective reality of the individuals
- (2) the focus on process and ambiguity
- (3) the focus on totality". (pp.776-777)

The first point of subjective reality of the individual has already been referred to. This method can allow the researcher to document how individuals make sense of and cope with the world around them and is a method which particularly lends itself to the examination of a complex and changing concept like autonomy.

The second point, "the focus on process and ambiguity", Faraday and Plummer (1979) expand by saying:

"The life history technique is particularly suited to discovering the confusions, ambiguities and contradictions that are displayed in everyday experience. It can therefore serve as a useful corrective to the mainstream of social science which locates uniformities and regularities".
(p.777)

The third point, "the focus on totality", is an antidote to the more usual sociological attempt to look at a tiny segment of life whereas here there is an attempt to see the individual within the expanse of his life experience, and the social and historical framework in which it is lived.

SAMPLING

The initial approach to sampling was by using the general practitioner's age-sex register. There was an assumption that social class is related to education and job aspirations, and that the views expressed by individuals are similarly related. An attempt was therefore made to reflect such differences in the catchment areas used. A large modern busy practice was chosen whose medical staff served two distinct communities. Each 'end', with its complement of district nurses, health visitors and clerical staff, operated independent systems of office management and records.

Permission was sought to look for patients of 75 years and over who had been in hospital and were now resident in the community. Such permission was granted to search the age-sex register and to make direct approach to individual patients. This permission was granted only after personal conversation with the senior partner followed by attendance at a group-practice meeting composed of both nursing and medical staff where explanation of the proposed study was given and questions answered by the researcher. This search of the register proved very time consuming and eventually, after excluding: those in hospital; those 'dead' on the shelves; those for whom no notes existed; those who had not consulted their general practitioner for three or more years; and those who had a psychiatric history, the numbers remaining were not very large. Some of the number were written to but a high proportion of those letters were returned by the Post Office as being "not known at this address".

About this time there was a development in the thinking about the true focus of the study and a decision was made to move from eliciting the patients' views about their movement between hospital and community to look more openly at autonomy and the experience of it over time. In this, the hospital experience was of diminished importance. Therefore, a major decision was taken to withdraw from the practice and to determine a different method for sample selection.

A clear breakdown of the results of the register search, as well as a letter of thanks for their kindness and encouragement, was sent to the practice. The patients who had already been approached were also thanked. There was nothing to suggest that this practice was atypical as far as the state of its records went and this process was thought unsuitable for the present work. A method of selection of a sample was therefore of importance.

The sample being sought had four characteristics: first, that the subjects should be 70 years of age or more; second, that they should have had some recent experience of being in hospital but not in connection with a psychiatric illness; third, that they were relatively fit and healthy and therefore were resident in the community; and fourth, that they did not suffer from a depressive illness.

Since the hospital experience was of diminished importance and the cause of their hospitalisation was also of little importance, it seemed inappropriate to attempt to choose a sample from patients in hospital about to return to the

community. The other traditional source of collecting subjects for nursing research concerning patients is community nurses. This means also seemed inappropriate since there was a desire to look at a group of elderly people who were relatively fit, both physically and mentally, and those being cared for by the community nursing service almost by definition would not be.

Another source which could have been utilised was the Social Work Department, either using social workers per se, the Home Help Services or Meals on Wheels. Again these agencies would be in contact with a client population which is, by definition, a troubled one and so this method was rejected. There is electoral register information which might have been accessed but since a very small group was being sought this would have been an irresponsible use of such data. It would have been possible to knock at a series of doors till an appropriate group was collected. Despite a high probability of gaining entry to people's homes by someone claiming to be a nurse, this option would have been even more irresponsible in the interest of the safety of the elderly and the good name of nursing.

The rejection of these options resulted in a decision to approach parish ministers on the assumption that they would know the old people in their congregations or parishes and would be able to suggest those who did not have psychiatric problems and who had had some experience of being in hospital but were presently resident in the community. Personal approach was made to two ministers, one in a city centre charge and the

other in a long-established suburb where the minister had been for a very long time.

The choice of parish ministers was a deliberate one because of the responsibility which parish churches have to provide spiritual care to all those of whatever persuasion, or none, who live within the bounds of the parish. Although the Church of Scotland within its national grouping represents a very broad theological spectrum, many individual parish churches will generally espouse a fairly "middle of the road" stance. This lack of extreme views was seen as an advantage since the likelihood of obtaining a group of people who were similarly autonomous or equally dominated by church dogma was remote. Too, the finding was accepted that a high proportion of elderly people claim a church connection and regular attendance (Brierley and Macdonald, 1985).

THE RESPONDENTS, THE MEANS OF CONTACT AND THEIR RESPONSE

The ministers were asked if they could suggest the names of people of 70 and over who were living in the community and had been at some time in hospital. The aims of the study were explained and they each asked to give the matter some consideration, though they were both enthusiastic and welcomed having been thought of as people who had both knowledge of and a concern for their elderly parishioners. They both thought it an important area for research, each expressing a concern for the manner in which elderly people seem to be ignored, at worst, or not consulted at an appropriate time, at best.

After a period of time had elapsed the ministers were contacted again; both supported the study and they each suggested their lists. They had in fact spoken to each person on the list and asked if there was any objection to "a nurse from the University" coming to speak to them. Only the names of those who showed some degree of willingness were forwarded. A letter (Appendix 1) was sent to all potential respondents asking if they would be prepared to take part in the study, and a date and time was suggested for the researcher to visit the respondent at home. An opportunity to withdraw was given, either on receipt of the letter or at the time of interview.

Both ministers suggested eight names. Unfortunately, two possible respondents died before they could be visited. Another of the ladies has been too ill to be interviewed. The remaining group of 13 is made up of eight ladies and the rest gentlemen. Though of course this is not a replication of the national statistics, it is interesting to have such a representation of men.

Most of the potential respondents contacted the researcher, either by telephone or by letter, to indicate a willingness to participate and to arrange a time at which the interview could take place. Only one lady after agreeing to see the researcher refused permission for a verbatim written record to be made and also refused to allow a tape recording to be made, but expressed a desire to help in any way she could! She certainly exercised both her curiosity to see the researcher and find out what the project was about but also her autonomy to participate on her own terms.

THE CONDUCT OF THE INTERVIEWS

After ascertaining that the respondent was happy to be involved in the study each life history was obtained. The shape of the interview was determined by the sort of information that the respondents divulged and the order in which it was revealed. Some questions were common to all the interviews, like the number of siblings; number of children; which parent made most decisions during respondent's childhood; choice of marriage partner; choice of first job; how decisions have been made in adulthood; and hospital experiences. Obviously there were very sensitive areas which took a long time to reach after the respondent felt at ease. Only one interview of the group was not recorded, in accordance with the respondent's wishes. The interviews lasted between one hour to four hours. Following each interview, notes were made about the circumstances in which each respondent lived. All the respondents were prodigal with their time and most were gracious in their hospitality. A commitment to let each respondent know how the information was used was given. One lady was interviewed twice (because of a tape fault) and in another case the interview had to be completed on a subsequent visit.

IMMEDIATE FOLLOW-UP

The day after each interview a suitable postcard expressing thanks was sent. Transcription of the tape recording was made by the researcher in long-hand. This allowed notes,

comments or questions to be made as the transcription proceeded. Subsequently this material was typed.

THE FRAMEWORK FOR ANALYSIS

The review of the literature of autonomy revealed the main themes which over the years have been important in defining and understanding the concept of autonomy. The themes or emphases which have been consistently reiterated over time have been thought, will and action. There appears to be no one else who has seen these dimensions as being intrinsically related to each other in a hierarchical relationship. This hierarchical scheme was used as the framework within which the life histories were analysed. The framework did help to demonstrate operational manifestations of autonomy in the life histories but also showed the viability of the framework itself. It is this framework which seems to have a particular importance not only for understanding nursing but also its practice.

SOME ETHICAL ISSUES

Research and Elderly Respondents

Though much has been written about the vulnerability of old age, Ratzan (1980) looks at that vulnerability with special relationship to the carrying out of research. Informed consent is one of the main planks in the protection of the objects of research. Informed consent has three requirements: to volunteer to participate; to be mentally competent; and to be fully informed about the study and its consequences. Further, Ratzan

suggests that for elderly subjects there be a fourth requirement, namely evidence of assessment of their understanding. If this is not available then a proxy consent must be obtained.

As far as the present study goes, it was assumed that the four requirements of informed consent were satisfied. The repeated seeking of co-operation from two different people (the minister and the researcher) with time gaps between seemed an adequate assurance of their willingness to take part. Too, there was objective corroboration that the participants were in good mental health and had no history of mental illness or confusion which meant that no proxy consent was required or formal evidence of understanding.

Another aspect which Wax (1977) cites as being particularly important in gaining informed consent is the difference in status between the researcher and subjects. He claims that in much:

"... biomedical and psychological research, the investigator occupies a position of such social superiority and moral power over the research subjects that they may feel coerced in complying ... (On the other hand) most fieldwork places the investigator in a position of social inferiority and moral dependency". (p.29)

In the present study there is little doubt that being a nurse gave licence both to go to individuals' homes and also to ask what, in other circumstances, might be interpreted as impertinent questions. It was hoped that the fact that interviews were held on the home territory of the subjects would help to redress the balance in favour of the subject

being in control of the situation. Probably more important was the fact that the researcher was an outsider and therefore was not part of the service which provided medical, nursing or social work care so that coercion could not be a valid fear.

The suggested difficulty of recalling potentially painful experiences or feelings by a researcher during a single intervention seemed to be answered by the knowledge that if this did happen another professional experienced in dealing with such situations was already involved with the respondents on a regular basis. There was, however, no evidence that the information sought provoked distress in any of the subjects at the time, nor was any subsequently reported to the researcher.

Keeping Secrets

Bok (1984) in her work on secrets has underlined the manner in which people manage information which they wish to keep to themselves. There is a possible difficulty since that may be the very information the researcher is seeking. There is a vulnerability we have all experienced when we have shared personal information about ourselves with outsiders, often at times of stress or distress or when our defences have been lowered, as by alcohol. Such experiences can be provoked by the ambience in which we are having an intimate conversation. Often it is in the cold light of day that the vulnerability strikes us.

The explanation of why some individuals appear to invite such trust is not clear but it is an ability which is of great advantage to a researcher. The inherent responsibility on the

researcher is an awesome one, and he must be sensitive and realise when it is inappropriate to probe or when it is possible to re-introduce a topic which has provoked reticence or silence. The way in which we deal with the vulnerability we experience by sharing information probably changes; such ability generally comes with experience and maturity. It is easy to assume that experience comes with age but this may be a fallacy for there are some individuals who have been little exposed to many outsiders or the sorts of situations when they might be tempted to share private information. In the instance of this study the researcher went to respondents' homes in an attempt to make them feel at ease for the very purpose of building a feeling of security. There were occasions when the interviewing was not as "hard" or aggressive as it might have been merely as a response to reticence or frank changing of the subject. It is salutary, however, to note the comment that:

"Both the distaste and the rationalization are self-protective responses, signalling the felt risks to discretion and to integrity from subjecting others to manipulative and intrusive research. As for the many social scientists who do such research they still have to reckon with suspicion and with studies damaged by false or mocking responses by persons who imagine that they are being duped and who retaliate in kind".

(Bok, 1984, p.243)

In the present study there was no evidence of "false or mocking responses", doubtless because the subject matter did not lend itself to such a response. One's own life story tends to be treated with a degree of solemnity. Naturally there were

incidents which provoked humour for both the person being interviewed and the researcher.

Lying

There is a possibility that there is information which one decides to keep secret. Sometimes the only way in which we can achieve our aim is to lie. There are many explanations as to why we lie. There may be a legal commitment to an organisation which makes us deny knowledge; loyalty to an individual; a need for confidentiality may make us speak with duplicity. In the health care setting it might be a will to protect a loved one from hurt that may make us not discuss a poor prognosis following a dreadful diagnosis. Frequently we do not tell the truth to children, the frail or the mentally infirm in order to protect them from knowledge which we assume they cannot handle or comprehend. Society would not hold us culpable for any of these examples of lying while claiming a conviction that it is wrong to do so (Bok, 1978).

There has been comment from nurses that patients lie (Melia and Macmillan, 1983). However, when these comments are investigated, the difficulty is not so much one of truth and its absence. Rather it is a difficulty of assessing the mental state of the patient. There is a feeling shared by large sections of society that the information given by the elderly, like that shared by children, needs to be checked. In this study there was an assumption that the respondents were completely able to control what information they shared. It was also assumed that they were telling the truth, though many

historians and some sociologists would have sought corroborative evidence from a variety of sources as to the veracity of the primary evidence. In this work no such attempt was made since the exactitude of when events happened was of little relevance to the subject under study.

Indeed, the researcher rested in the assurance that what has been shared is how the individual has made sense of all the experiences that make up the tale. It is how it seems at the time of telling, and so is true. Each telling may alter feelings and possibly interpretations, since neither feelings and therefore interpretations are static. But that does not negate the fact that that is how it is at the time of telling. It is of course also recognised that many people repeat stories identically time after time.

In this connection it may be of interest to note here that there was difficulty with one recording session when a tape fault resulted in a completely silent tape. The lady involved spontaneously offered to repeat the interview at another time. This was done and large sections were recalled using the same or very similar patterns of telling and order of views elicited. On the first occasion the lady had been asked whether she had decided not to get married. After replying, she commented that she had never talked about the episode before and went on to say, "But then I suppose nobody else has ever asked me before!". Inevitably the researcher wondered if she would after a lapse of time re-consider talking about it but any fears were unfounded, and she even verified that the researcher was the first person to raise the matter.

Protection of Confidentiality

As has already been indicated, informed consent was obtained. Support was available to respondents who might subsequently feel vulnerable or hurt. The veracity of the life histories was accepted and the respondents were assured of this. The interviewing technique was not aggressive. Secrets were not probed. Confidentiality of the respondents has been protected by means of neither using their own names nor indicating who suggested them. Very revealing information has not been included in the case histories. They have all been told that they will see what has been written about them. Some asked that no one else should hear their tape recorded voices and of course such requests will be respected. One person, however, wanted a copy of his tape. This request has been acceded to.

Such means of protecting the respondents and the information which they shared made it possible to pursue the study of an abstract concept. The very nature of the subject demanded the employment of qualitative method and the life history method in particular, with its inherent strengths and weaknesses. Though there are intrinsic problems in carrying out research on elderly subjects, those involved in this study were capable of looking after their own interests. These respondents all gave informed consent and care was taken not to coerce them. In cases where there was a spouse still alive, both partners were involved at some point in the interview and were present either for part or all of it.

CHAPTER 4

Case Studies

OVERVIEW

The life histories showing operational manifestation of autonomy are given, and listed against the hierarchical schema of the dimensions of autonomy. The data collected by using the topical life histories are discussed in light of the dimensions of autonomy. Some questions were common to all the interviews, like the number of siblings; number of children; which parent made most decisions during the respondent's childhood; choice of marriage partner; choice of first job; how decisions had been made in adulthood; and hospital experiences.

All the names of the respondents have been changed so as to protect their anonymity. Also any other particularly identifiable names or places have been omitted. In all other respects, however, these case studies are as they were told to the researcher.

LIFE HISTORIES

Mrs. Taylor

Mrs. Taylor, aged 85, was third of four girls and two boys. Her father was an influential man in the community. He and the elder son served in the First War. Mrs. Taylor went to a girls' school and was hoping to go to London to drama school when she left but, because of the war, this did not materialise. Instead she took a crash course in secretarial studies and subsequently worked for a prominent court judge who was a close family friend. In her early twenties she was asked to be national president of a youth organisation. In connection

with this work she met her future husband who was several years her senior. They married 18 months after their first meeting. He was already a parish minister when they married. She took over the running of the manse with the help of staff. Two children followed fairly quickly. Both children were born at home with the help of a private nurse. These children, a boy and a girl, are each successful in their chosen professions. Mrs. Taylor ran various church organisations, planned family holidays and various other domestic matters. During the Second World War she was organiser of various war-related efforts for the community. She has been a widow for 20 years. She decided to move to sheltered housing because of failing sight and increasing lameness, as well as the loss of an excellent housekeeper. The sheltered housing was in a different part of the country, but nearer to where her son and daughter-in-law live.

Mrs. Taylor has suffered a lot of illness over the years. Latterly, several periods of hospital treatment have been caused by accidents compounded by crumbling spine and joints. She also experienced loss of sight in one eye 30 or so years ago and more recently the sight in the other has so diminished that she has been included on the blind register. Now she is largely confined to a wheelchair. Despite her physical problems she is totally in control of her situation, though she talks of being not trained for anything and of being an old crock.

Miss Luke

Miss Luke, aged 80, was the youngest of a family of two boys and two girls. Her father was a sheet metal worker of gentle disposition. He ended his working life being unemployed as a result of his company moving to the other side of the country and not being prepared to travel. Miss Luke left school at 14. She then went into service for a family where she did not like the man of the house. At 18 she decided to become a seamstress, partly to find a more satisfactory work environment. She worked on and off for the same firm for 41 years. Especially latterly, she had quite a bit of responsibility when, for example, people in more senior positions went off on holiday. When she was 30 years of age she received a proposal of marriage which she turned down. The reasons were that she felt she could not cope with the problems of being married to a merchant seaman. She also gave the impression that she was not sure that she would entirely trust the man's fidelity when he was away. Since her only sister went to Australia at an early age, she assumed full responsibility for the care of her parents till they died. About two years after her father died, and in response to financial constraints, she alone went and found a new, smaller house for her mother and herself to live in. Her mother was never really happy there. Miss Luke has lived there alone since her mother died.

Over the years she has suffered a lot of pain. She was knocked down by a car when she was young and had a lot of

trouble with her back for a number of years. When she was 34 she had a hysterectomy, not very long after having had an oophorectomy. Both these operations were paid for by other members of the family. Ever since the hysterectomy she has suffered from bowel problems. She still suffers from chronic constipation and has had various periods of hospitalisation which have not been able to offer permanent relief. She has an enema and/or suppositories at least once a week. Sometimes the community nursing services have been called out during the night to attempt to help her.

Miss Luke has not been out for seven years after complaining to her general practitioner about being dizzy. He suggested that perhaps she should not go out alone. Though various people suggest that she should be in sheltered housing, she is very reluctant to give up her home where she is surrounded by her things and her memories. She manages her own cooking but has a home help who does her shopping and some of the cleaning.

Mr. Thomson

Mr. Thomson, aged 80, was the oldest of three boys. The youngest died of meningitis when he was about five years old. The other son left home at a fairly early age, first to work in Liverpool, then Switzerland and finally Canada, where he settled and married. His father was a cashier and he worked for the same firm as a joiner, having left school at 15. He was unhappy, having wanted to be an architect or draughtsman. When misdemeanours were perpetrated against him by his workmates, he

was not above going to his father to report them. When Mr. Thomson was 21 he was on holiday and at the same time his parents went to Switzerland to see his brother. During this holiday his mother was taken ill and died following two operations, without him seeing her during the illness. The father and son then had a series of housekeepers to help run the house. The last of these, after taking the position, refused to sleep in the box-type room allotted to her and insisted on a bedroom with a window. So Mr. Thomson and she had to exchange sleeping accommodation. She then got into the habit of letting the fire in the kitchen go out and asking if she could join the men in the parlour in the evenings. Mr. Thomson resented this strenuously. One day the housekeeper asked if she could have a week's holiday which was granted. The first day she was away his father suddenly announced he too was going on holiday. They returned married. Almost inevitably relationships became very strained.

When Mr. Thomson senior retired he suggested that his son should stop work too. This he did. He has never been in full-time employment since. When his father died, Mr. Thomson went out less and less often in order to protect the house and property from the widow. There were various legal wrangles about whether or not he would be re-housed. He now lives in a single room in very poor conditions. He claims considerable domestic skills, learned from watching his mother. Mr. Thomson, however, has clear ideas as to job description and will not, for example, put the fire on because it is the job of the home

help. The home help is obviously very good to him, doing washing three days a week, cleaning, shopping, bringing the newspaper, and, during the interview, bought and brought home in great triumph a new chair from the local junk shop. Mr. Thomson never married because he was not keen on the idea and preferred to be on his own.

He is unsteady on his feet but, though he reported several falls, so far has not come to any great harm. He has no great fear of falling and admits to being prepared to lie, if he should fall, till help comes. He has been in hospital several times recently with leg ulcers. Too, he has been suffering bladder difficulties. He is supposed to release the indwelling catheter hourly to prevent leakage but this he will not do despite encouragement and presumably discomfort, not to mention the smell. A male district nurse pays a weekly visit. His home help visits four days a week and on the fifth day he goes to a day hospital. His great comforts are the radio, television and, above all, his Persian cat. During the time he was in hospital the last time his room was repainted, and a new bed and an electric water heater were installed, which obviated him having to operate with a kettle on the fire.

Mr. Stirling

Mr. Stirling, aged 70, is an only son with one sister. After school, which he left at 16, he went into the bank, though his parents wanted him to go to music school or art college. He was accepted by the bank for an apprenticeship on the strength of a golf handicap of 4. He and his wife knew each

other as children. She was the minister's daughter. Although he had decided when he was eight that he was going to marry her, they discussed at 16 whether or not they would marry before the war but decided to wait till after it was over. Mrs. Stirling's parents were concerned about the friendship because of her age. Mr. Stirling was 26 when they eventually married after his war service with the good-will of both families. There are three daughters of the marriage, one living abroad. He has been retired for five and a half years. These years have been very full and have included moving to another part of the country from that in which they have spent most of their married life, and becoming very active in the new community.

Mr. Stirling has waged many campaigns on very varied matters, including seat rents (a now outmoded means of contributing to church funds and securing a seat in church by paying for it) and a by-pass road. He is an articulate but careful man and does a great deal of research on any matter or cause he chooses to take up. He has been a church elder for many years and this church commitment is very important to both Mr. and Mrs. Stirling. He has recuperated well from his illness and is leading a very active community life.

Mr. Carlisle

Mr. Carlisle, aged 70, was an only child. His father died when he was ten and his mother when he was 22. When he left school he went to university to study zoology. On completion of his degree he was offered two posts, one a permanent teaching job and the other a research post for one year. He accepted the

latter because he was attracted to research. This led eventually to a permanent university post. Being on his own by this time, he discussed this decision with no one. Mr. Carlisle and his wife married shortly after they met. He returned to academic life after the war. Though now retired, he is still involved in a long-running project. The Carlisles have one daughter and two sons. Mrs. Carlisle looks after two of their ten grandchildren every day for their dentist daughter. Though she enjoys this, she finds it confining in that she is not out and about, and therefore has little to talk about. She also gives quite a lot of care to an elderly neighbour.

Mr. Carlisle had a rectal growth removed (with two operations necessary because of severe bleeding), from which he recovered well. He is now leading a very independent and busy retirement. He cycles about the city, covering around 50 miles a week.

Mrs. Sheild

Mrs. Sheild, aged 78, is the daughter of a lawyer son of the manse who was a strict Sabbatarian. There were two girls and two boys in the family, Mrs. Sheild being the only survivor. She left school at 17 and, though she wanted to study music, went to work in a hospital for the mentally handicapped. She was so unhappy that she left and went to work as a housekeeper-cum-cook. Subsequently she started nursery nursing. Mrs. Sheild met and married, without parental approval, a gardener who lived near her home. Her mother eventually accepted the marriage which lasted for 55 years and on the

whole was happy. The Sheilds spent their working life in tied houses connected to estates. They had seven children. One little boy died in infancy, having been ill all his life. All of the remaining children retain close contact with her and have been successful in their own lives and marriages. Mrs. Sheild ran the house, undertook the discipline and generally made decisions, despite Mr. Sheild having a quick temper.

Mrs. Sheild has had a lot of illness, including a hysterectomy during which a ureter was severed. It was subsequently transplanted but this caused constant incontinence which lasted for many months. The strain of this, complicated by the demands of a large family, told and one day after an argument with her husband she took an overdose. She escaped prosecution because of her medical history. She was very firm that psychiatric treatment was not called for. Subsequently the kidney was removed, but only after further illness was evidenced by very high blood pressure resulting in violent headaches and a stroke-like episode while on holiday in England. Mrs. Sheild refused to be treated in England and insisted on returning home, which involved her first aeroplane flight. She has also suffered alopecia, of unknown origin. Relatively recently she had a hip replaced and her home help came just after her return from hospital to find her papering her kitchen.

Though widowed four years ago, she remains independent and forceful. There are times, however, when she admits to feeling low. On such occasions she telephones one of her daughters and

asks her just to talk to her. Mrs. Sheild travels around to see her various family members and the grandchildren come to visit her. Every day she still does a national newspaper crossword.

Mr. Bain

Mr. Bain, aged 74. Being the only son of the house, and despite the resulting financial difficulties, he was sent to one of the ancient universities to continue his education. He got an honours science degree for which he worked hard in response to the obligation he felt toward his parents. After completing his degree he did two years' practical training. Then he met his future wife through their mutual church connection. Their decision to marry was a difficult one because of the impending war, though there was no likelihood of military service because of the sort of employment Mr. Bain was by then involved in. Subsequently, he rose to be chairman of a major part of a nationalised industry. There are four children of the marriage, three girls and one son. Three live in Scotland and one abroad. When Mr. Bain retired, he and his wife moved to the country but with increasing years, arthritis and because of the inherent problems of running a house with a large garden they moved to the city where one of their children lives.

Both Mr. and Mrs. Bain have suffered a good deal of ill-health, particularly recently. Mr. Bain has had both hips successfully replaced. Recently he has suffered a lot of pain following a bowel resection and subsequently a colectomy. Most recently he had further abdominal surgery after 15 earlier

'stoppages' which cleared spontaneously after sickness and pain. Mr. Bain's pain is not treated with any analgesia because no drug suits him. Only with reluctance was permission given for his last operation. At present, Mr. Bain is very adamant that he does not wish to undergo further surgery. He has faced the reality and possibility of death if surgery were refused. Though his wife would prefer him to give permission if the need arose, she admits to understanding his reluctance and gives the impression that she would not force the issue.

The church connection is obviously profoundly important to this close couple. They discuss issues together, but in the light of a strong religious conviction and practice. Mr. Bain also sets great store by responsibility and duty. Only one of the children has maintained a church connection, which has caused some sadness and contemplation of failure because they tried to teach by example. But the more potent factor may be the respective partners the children chose.

Mr. Carter

Mr. Carter, aged 85, one of a family of one girl and three boys. The youngest boy was killed when he was 19 in the First War. Their father was a shoemaker. Mr. Carter had a knee injury when he was three which was badly treated and which has resulted in him having the knee joint removed. Inevitably, his condition precluded military service. He left school at 16 and started work for a whisky merchant. He went to night school and, amongst other things, learned bookkeeping. Eventually he ended up working in a dairy until retirement.

Despite his bad leg he used to do a lot of dancing and for a while ran a boys' football club. Mr. Carter contemplated marriage but, though he thinks he could have been married, he relished his independence more. If he had married, he would have liked children and thought it important to spend time with them. He lived with his parents till they died, first his father and then his mother. During the 35 years that have elapsed since, he has been alone. He enjoys cooking, but now his home help deals with cleaning, washing and shopping.

Mr. Carter has had a lot of orthopaedic problems over the years. He also lost the sight in one eye while he was still working and now the state of his eyesight prevents him from reading much. Most recently he has been in hospital with prostate trouble. Altogether he is much irritated by not being able to get about because of the height of bus steps and the lowness of cars. Despite his incapacities, he is very independent. He describes himself as being so and feels that he was born that way. He is rather cantankerous and, though he has made a will, he was threatening to change it to prevent those who have recently ignored him from getting anything.

Mrs. Macpherson

Mrs. Macpherson, aged 71. Although she said she was willing to be interviewed, at the time she refused permission to make a tape recording or verbatim record. Subsequently she wrote and offered any help she could give. Mrs. Macpherson is one of several children of a crofter from the Western Isles. She trained as a nurse in the central belt of Scotland. She has

been married, with two children. When she was widowed she moved into sheltered housing as a warden and has remained there since retirement. She had a long period in hospital following being knocked down by a car.

Mrs. Duncan

Mrs. Duncan, aged 77, the third youngest of a family of 13 whose father was a dustman. She left school at 14 and went to work in a sweet factory. The Duncans have been married for 60 years and have one daughter, five grandchildren and eight great-grandchildren. Mr. Duncan worked for many years in a garage and his wife as a school cleaner. After marrying, they lived in the same area of the city centre in which they were born and brought up. Mrs. Duncan was in hospital five years ago when the owner of the flat they had lived in all their married life repossessed it. The local council re-housed them on the outskirts of the city. All of this happened without her knowledge. Both Mr. and Mrs. Duncan have kept fit, but Mrs. Duncan has twice been in hospital in the past five years, although now claims to feel well. Mr. Duncan does most of the housekeeping, including the cooking, though they shop together and call on a granddaughter who drives them home. They go out very seldom and cannot remember when they last went to the cinema, which used to be a great pleasure. Mr. Duncan answered many of the questions, though his wife did have views and differences of opinion but she easily acquiesced to other views. There were times when they bantered with each other about such matters as why they had married. Mr. and Mrs. Duncan

both feel that they have had a good life, though there are financial problems now, provoked particularly by the cost of heating their house.

Miss Bruce

Miss Bruce, aged 80, youngest of a family of ten. Their father worked in a newspaper machine room. Miss Bruce left school at 14 and went to work as a clerk in a merchandising business. She stayed there until the war and then got a job with a similar organisation against parental advice. With her new job she went to London where she found great liberation. This was the first time she had lived away from home, though by this time she was 40. But at the end of the war, though she would have liked to stay in London, a sense of duty made her return to her newly widowed sister and her father, being the only unmarried child. Miss Bruce knew that she was not going to look after her eldest sister when she was widowed because she was a dominating lady and would have been difficult and lazy. The only way to solve this problem was to get her into an eventide home against her wishes, a solution which she achieved. Too, when the time came, she arranged that this sister's funeral should be private without reference to the rest of the family who were not pleased with the decision. Miss Bruce decided not to get married because she was not sure that she would be able to carry out her promises and to do things that she ought to be doing.

She had a wide circle of friends with whom she golfed and went country dancing till well into her seventies. They also

went regularly to the theatre. She has kept good health except for cataract problems. The last time she was in hospital she did not tell any of her family that she was being admitted. Miss Bruce feels that she could have done a lot more with her life but that family responsibilities supervened.

Mrs. Paton

Mrs. Paton, aged 82, one of six children. Her elder brother died when he was seventeen and a half in the war. When her mother died her father remarried a woman with three children of her own. It was made clear that the daughters of the first marriage were not wanted and so their father told them to go but kept their brother. The second marriage seems to have been unstable and the girls were expected to sort things out when their stepmother and father parted, which happened on several occasions. After leaving school at 14 and several jobs, she took up hairdressing with the prospect of going to Australia but because of the depression this never materialised. Mrs. Paton decided not to marry until her sisters were married out of a feeling of responsibility towards them, but also because she did not want to rush into domesticity. There are two sons of the marriage, both happily married and successful. The family lived two floors up in a tenement and when Mrs. Paton developed heart trouble this became an increasing problem. Mr. Paton was a keen bowler and when they were returning home from a bowling match they saw a sheltered housing complex being built and, after looking at it, decided to put their names down and got a flat as soon as the unit was

ready. A year and a half later Mr. Paton died and his wife has continued a busy life with lots of contacts with her immediate family and the other inhabitants of the unit. Her sister and her husband also live in the complex. Various of her neighbours call and chat while their washing is being done as Mrs. Paton lives near the laundry facilities. Mrs. Paton has recovered well after an operation recently and copes beautifully with the assistance of a home help. She is a very contented and serene lady.

Mr. Strong

Mr. Strong, aged 80, an only son who left school at 15. He is a retired policeman. The Strongs have two children. It is an obvious pleasure for Mr. Strong to recount a vast fund of stories about the past and he has a keen memory for streets and incidents in his past experience. Towards the end of his career they moved to their present house, mainly because of its garden. He was a great gardener but his recent illness has curtailed this and now Mrs. Strong does it. One of his great pleasures was his car but the doctor has prohibited him from driving, which he finds very difficult and indeed he obviously does not like talking about it. Now he spends a lot of time sitting chatting to friends. His church connection has been important to him all his life. Mrs. Strong takes great care of her husband and his diet. He remains every inch a policeman and is a very precise and determined man in the sense that he will persevere with any matter till it is explained or resolved.

LIFE HISTORIES IN LIGHT OF THE DIMENSIONS OF AUTONOMY

Each of these elderly people can be described as autonomous. They have each lived very normal, busy lives. Within the group there was a mixture of those whose main task had been wives and mothers with the inevitable day-to-day decision making, and those who were wage earners whose decisions were often of a different sort. Now retirement has brought changes to all of them, including the married women. Each person displayed a continuation of a state of independence since they were all in the community coping with life, though with the support of home helps and the community nursing services. The complications of ageing had provoked three of the group to move into sheltered housing, but in each case the decision to do so arose from a personal realisation that an increasing security was right for them.

In light of the dimensions of autonomy their biographies are revealing. Since autonomy of thought is the base line, evidence of this dimension was sought first. It is a reasonable claim that they all think for themselves. None had difficulty in conducting the conversation, remembering incidents and recounting them. To some extent each respondent was prepared to try and think about the fairly abstract idea of how decisions are made. Only with one, Mrs. Duncan, was it unclear how much thinking was being done, in the sense that she was the most willing of the group to let the researcher guide the conversation rather than exhibit the freedom to follow her own trains of thought. Though even she had no problem remembering

the past; for example, she remembered clearly what both she and her husband had worn at their wedding, including his carnation and the shape of his shirt collar, over a period of 60 years. She made it obvious that she had coped with the recent vagaries of living and was making the best of her situation. She was apparently in control of herself, though everything spoken of was with reference to her husband. Thus it appeared that she had some autonomous thought, though it was unclear how far this extended.

To move to the middle dimension of autonomy of will there is evidence of limitation in several cases. Mrs. Duncan has relinquished the general tasks of housekeeping to her husband. She goes nowhere without him. Their granddaughter, who has a car, appears to be the person who provokes Mrs. Duncan to go out by calling to take her or by taking her back from shopping. All this is in spite of her illness not being the sort one would expect to hamper movement. Of course the move to a new area from the place where one has lived for 70 or so years cannot be underestimated. Too, the cost of travel from the outskirts of the city to the centre where they had previously lived and the problems of public transport are not inconsiderable. These factors have had a considerable impact on their social contacts.

Mr. Bain provides another example where there is evidence of diminution of autonomy of will, though less marked than in the first instance. He is finding it increasingly difficult to make himself go out. From a mild altercation with his wife he

revealed that he found it hard to summon energy even to welcome unknown people to the house. He gave permission for his last operation against his own judgement, mainly because his wife was not present compounded by the doctor seeking the permission responding to the question, "What happens if I don't sign?", saying, "You just die!". Mr. Bain claims no such doubt now; he would not sign the permission slip despite the knowledge that no intervention would result in death, although there is some doubt in the researcher's mind that this would be the case.

Mr. Strong provides another example of people who, following illness, have become increasingly reluctant to go out. Because of having had to give up driving while suffering a measure of disability and being a distance from the bus stop he has an excuse. Another facet of Mr. Strong's history is that the present is much less real to him than the past and he clearly enjoys talking about the past. The visitor who called during the interview had obviously heard some of the reminiscences before. Mrs. Strong made clear what he could eat from the plate of shortbread and cake supplied for afternoon tea, thereby taking away the sort of decision making that is enjoyed almost without exception. This action on the part of the wife was not inhibited by the presence of the visitor or the researcher.

Perhaps the most extreme example of limited autonomy of will is provided by Mr. Thomson. He is content to sit in a very cold room despite an adequate supply of coal readily to hand. The window was left open to allow his cat access despite the

fact that the cat was curled up on the bed fast asleep. Also Mr. Thomson was apparently reluctant to release his indwelling catheter regularly resulting in leakage and therefore wet clothing and chair, not to mention the pervading smell of urine. The interference with his will may have arisen from a variety of sources but certainly it was the problem of will that prohibited action. These problems would almost certainly have been lessened with regular help and support.

Miss Luke also finds it impossible to get out and has not done so for seven years, except for visits to hospital. Having got medical licence not to attempt to go out is possibly merely convenient. It is not clear how much dizziness she suffers in the house but Miss Luke felt that the home help did not make a completely satisfactory job of cleaning under the bed which Miss Luke was happy to rectify on her hands and knees. Thus there is an impediment of will on one level but not on another. It must be noted that she has withdrawn not only into the house but into one room, having moved her bed into her kitchen-cum-livingroom. Every surface gleams and there is an almost cold, austere appearance to this room which faces the backs of other tenements in a square.

Others of the group spoke about not going out as much as they did when they were younger, which can be interpreted as withdrawing from the world. Their reasons were of the sort that a fear exists of being alone on the streets at night. The number of muggings and the imprudence of opening the door to strangers were mentioned in this connection too. These reasons,

though regrettable and perhaps not totally appropriate, seem to be rational enough not to indicate an interference with autonomy of will. Indeed they are an indication of doing things on the basis of thought, including what is right for the individual. Too, several of the group spoke of the financial straits that old age had brought. The cost of living was much spoken of, with particular reference to the cost of heating and entertainment, combined with the diminution of the places of entertainment which means greater expense in getting to theatres or cinemas. The ubiquitous nature of television but dissatisfaction with the sort of programmes available results in alienation and partial withdrawal from the world as perceived.

The examples already mentioned do suffer to some extent from a limitation of the third dimension of autonomy, that of action. The evidence of this is largely of a diminution in movement outside their homes but, as has already been shown, some have diminished activity within their homes too. Of the group there are three, Mrs. Taylor, Mr. Carter and Mr. Strong, who have a limited degree of autonomy of action.

Mrs. Taylor needs help with most of the activities of daily living because of not having much movement or power in her legs which largely confines her to a wheelchair. The other element that is important is her lack of sight in one eye and diminished sight in the other. She, however, has no limitation of autonomy of will or thought. She is well able to dominate her life by having other people do things for her. She has a

large group of people, including the staff of the establishment in which she lives, and her family and friends who visit very frequently, to answer her telephone messages, do her shopping and even take her out, sometimes on quite extended journeys.

Mr. Carter has curtailed autonomy of action because of his orthopaedic problems which prohibit him getting on and off buses, using cars or walking very far. He also has diminished sight. His confinement to the house is not a matter of choice. The main difference between these two people is that Mrs. Taylor has been able to manipulate people and circumstances while Mr. Carter has just got angry about it and, being fiercely independent, becomes belligerent. He has not been able to allow himself to accept help and get people to do things for him.

The third case, namely Mr. Strong, is confined by his lack of will compounded by his heart disease and the over-zealous care of his wife which diminish his autonomy of action.

From the evidence elicited from this group the hierarchical schema of autonomy certainly seems to hold. They all have autonomy of thought but those who have diminution or limitation of autonomy of will have necessarily a resulting limitation of autonomy of action. But it must be underlined that it is possible to have limitation of autonomy of action while retaining unimpaired autonomy of thought and will.

The limitation of autonomy of will, it would appear then, is the most fragile and perhaps most influential of the three.

Here it has been suggested that there are examples of limitations of the will being caused by permanent discomfort if not outright pain, domination by a spouse or anger with the past, or romantic notions of the virile young man who has degenerated into a useless old one. One spoke quite clearly about wanting to die and such a wish can so dominate autonomy of thought and will that patients do die.

Autonomy of will is the dimension that the outside observer does not much think about. A possible explanation for this is that our socialisation makes us feel reticent about pursuing or probing any mental inability. Nurses are no different in this respect from the rest of society. Indeed it might be that nurses have an added difficulty in that they not only bring to the care of people their family socialisation, but also the views of their profession about the mentally ill and handicapped, and the elderly. Though there are exciting changes afoot, particularly with regard to the views about and care of the elderly, it remains true that there are still many nurses in practice, increasingly at managerial level, who have not had much if any training or specialised practice in geriatrics or, more commonly, in psychiatry. With the changes in nursing education it can be hoped that in future nurses will be better equipped to explore difficulties in the domain of the mind.

CHAPTER 5

Making Decisions

OVERVIEW

This chapter draws together some of the elements that various respondents commented upon as they spoke of how they made decisions, about their childhood experience of parental decision making and finally their decisions which relate to health care.

INTRODUCTION

Respondents were asked how they made up their minds about things. This was something that they all found fairly difficult and indeed some said "I don't know" and it was only after returning to the subject later in the interview that they could begin to explain the process. Others never got round to dealing with the abstract concept of decision making, but in the process of talking about decisions they had made in fact revealed aspects that they found important. One of the noticeable interesting features was that the educational background of the respondents had little influence as to their dealing with the question, nor had the number or sorts of decisions they had made during their lives. Perhaps the most important thing to note is that it is clear that over the years positive decisions to do things were relatively easy and did not require a lot of thought. Whereas for negative decisions, such as not to marry, even after 50 years the pros and cons are still easy to rehearse. Thus one has the feeling that these were hard decisions.

When the interview agenda was being thought about it seemed possible that the person who had made decisions at home when the respondents were young would have an effect on their attitudes to decision making in later life. Therefore questions about who had made decisions at home were included.

The desire to know about how autonomy affected the health care decisions that various respondents had made arose from the knowledge that this group was born in the days of private medicine and charity health care. The group was chosen from two districts which threw up people of very different financial standing. This chapter will end with information gleaned on this topic.

SOME ELEMENTS IN DECISION MAKING

It Takes Longer

Q. "I wonder could you tell me how you make up your mind?"

R. Not really. But one thing I can tell you. When I worked I had to make decisions all the time and I never really thought about it. But now it takes a lot longer to decide about things.

Q. Do you mean everything or just some things?

R. Oh, everything. Yes, everything takes longer. I've got to think about it."

Perhaps the most striking element which many felt was that making up one's mind takes longer with increasing age. This is of immense importance when caring for the elderly. Since the bulk of the caring, particularly of those who are ill and have some impairment of will, is done by younger people the time element is possibly forgotten. It might well be this element,

more than any other, that makes elderly people feel rushed and that nurses have little time for them. Of course it might be that there is another explanation rather than simple ageing. As one of the other respondents pointed out in reply to the question:

Q. "Do you find it hard to make decisions?"

R. No, but then I don't have any big decisions to make any more. They're all made already".

It might well be that because that gentleman is fundamentally in good health he is right when he says that he feels that there are no major things left to decide, but of course with advancing years major decisions may yet have to be made. It may be that the process is slowed if there is lack of practice and, of course, it is quite difficult to practise theoretically. Too, the realisation that it is taking longer when required may, in fact, become one of the inhibiting factors in decision making.

Another example of the same sort of thing came from one of the ladies. She was approached by the superintendent of the special housing unit in which she lives and asked if she would like to move downstairs. The larger room being offered would be altogether more convenient because of her wheelchair and it was also on the same level as the communal facilities. There was, of course, one potential problem, namely that of increased cost. Her immediate action was to reply:

Q. "You said, 'Well I'll have to discuss that with my son and my lawyer'.

R. They are the one person!

Q. Well, yes.

R. Oh, I mean I've always done that. I don't ... I mean I would make up my own mind about it.

Q. Well I'm sure you did.

R. Yes, most definitely ... I wouldn't do anything without telling him. That is one thing.

Q. But you would make up you're own mind.

R. Definitely. Very often maybe make up my mind differently from what (son and daughter-in-law) would do. They don't like it I think."

In reality she knew that there was no financial problem at all. She readily agreed to the researcher's subsequent suggestion that in truth she was 'buying time' to let her think about it. Though she claimed to discuss issues with her son, there were obviously times when it was not really a matter of discussion, but rather the means of intimating a decision already arrived at. Of course such a technique can be a means of checking that one's ideas are not faulty when one has the arguments and logic confirmed by another whom one trusts. This is an important service which nurses can fulfil. The fact that the lady claimed the need to discuss the matter with her son and lawyer may have been her way of securing the superintendent's willingness to wait for an answer.

I Can't Decide

Q. "How do you think you make up your mind now?"

R. Very airy fairy. I can't make up my mind. I have been looking for a dress and I've been looking for months for a dress and I can't make up my mind to go in and get one, even to try one on. I just go round looking. Now that wasn't me before."

There were some who, though they pointed out that their work had demanded instant and frequent decision making, now claimed that they found it more difficult, if not impossible, to come to decisions at all. These people fell within the group that the research suggests have impaired autonomy of will. One would expect that they would inherently find it hard to make up their minds. Obviously it is not a major disaster if one cannot make up one's mind to buy a dress but it might be a great problem if one cannot decide where to live.

Weighing Things Up

Several of those interviewed spoke of weighing things up, as here:

R. "I made my own decisions.

Q. You did?

R. I could always do (make) my own, yes.

Q. How do you make decisions? How do you make up your mind about things? What you're going to do?

R. Take all the facts and weigh them up and see what you should do".

And again:

R. "In other words to come to decisions on ...?

Q. Well either big things or wee things - anything.

R. We never rush into anything. We would think carefully before we do anything.

Q. And have you always been like that?

R. It's my nature".

The realisation that some take everything into account is a salutary reminder of the important element in the definition of autonomy of thought, namely the ability to think rationally.

It is also important for those involved in the nursing or medical care of people to remember that no proper decision can be made in the absence of knowledge, since without sufficient information no rational mental debate can take place. Another aspect to underline here is that often the patient does not know the right question to pose which will produce information. But to ask a patient, "Do you understand?", is equally unproductive of useful information on either side. For such a question makes it difficult for people to give a negative response and equally there is no certainty on the part of the professional that understanding is present.

I Talk To ...

Q. "And how in your marriage have you made up your mind about what to do and how to do it? Who do you think has been the boss here?"

R1 Usually we both decide.

Q. Do you? You decide together.

R1 Aye.

R2 Nobody's the boss. We decide together".

All those of the group with spouses present gave an almost idealised picture of couples talking everything over together. Obviously for those in such a situation this is good. Two of the widows talked about speaking to their dead husbands out loud:

Q. "Do you talk to other people about decisions?"

R. I should say so.

Q. But I mean do you talk to friends, or do you talk to any particular one of your children?

R. No. I wouldn't say I talk to my friends about making up my mind. I talk, I think, I take advice from my children.

Q. Mm.

R. I've never been able to spend a lot of money.

Q. Mm.

R. Because we never had it and my husband was very careful ... I still have a guilty conscience if I'm spending and ... I can hear my husband saying 'You don't need that, you can do without that'. And I won't buy it because old habits die hard.

Q. Yes ... Do you talk to your husband now?

R. Yes, frequently.

Q. Mm.

R. Oh, I'm watching television if it's a good programme. I'm going (turning towards a photograph) and saying 'You would have enjoyed that'. I mean he's still here as far as I'm concerned".

The second widow made a similar remark but when she realised what she had said she commented, "Well at least I think about what he would have wanted me to do". Perhaps we in the health care professions need to be more sympathetic towards elderly people who speak ostensibly to themselves. Certainly it would seem to be true that both manifestations, that is to say contemplating what a dead spouse would have said and talking out loud to him, are real.

The widows with children and some of the couples appear to talk to a selected child about problems to be solved or decisions to be made:

Q. "But do you think you talk to other people when you are making up your mind about something? Presumably you talk to your wife?"

R1 Oh yes, oh yes. We have always discussed everything together. I tell my wife the most trivial things that have happened when I go home. Don't I, dear?

R2 Yes.

R1 I tell her who I have been meeting and so on and so forth.

Q. If your wife weren't here who do you think you would talk to?

R1 I suppose my daughter really - we are in very close contact. But it wouldn't be the same. Nothing would be the same.

Q. Mm.

R1 Yes. She's a wonderful person.

Q. Fathers and daughters are often ...

R1 Well, she's our only daughter".

In some instances the choice is obvious as in the case of the nearest child, in others it is the girl as opposed to the boy, and sometimes it is the child who has married the nicer partner. But there are some choices which are apparently inexplicable. All these examples underline the need for professional carers to treat people as individuals and exercise caution in not jumping to the conclusion that one or any relative is the right person to involve in discussions.

Sometimes professional carers feel it incumbent upon them to offer advice. One of the group had had quite a number of decisions made for him which caused the researcher to ask:

- Q. "Do you mind people telling you what to do?"
- R. No, the nurses in there were all very nice.
- Q. I was thinking of somebody like the home help too. She was telling you to put your fire on in the morning.
- R. I have to wait till I have my breakfast before I clean out the fireplace and set it. By the time you do that it's getting on for dinner time and I say, 'Och, I'll wait till I get my dinner and I'll put it on'. Which is 2 o'clock.
- Q. So it doesn't really make any difference?
- R. No, it doesn't make any difference. I mean you move about during the day, the forenoon. It's not like if you're sitting down.
- Q. Do you feel the cold?
- R. Well the point is I like to put the fire on just after dinner time.
- Q. Have you always done that?
- R. Always done it. She usually does it for me when she comes. Well why should I do her work? I don't mind doing it on a Wednesday after ... (the day hospital). But why should I do their work? I don't know what she does. It was after dinner time that she came today. I know she goes to two other houses. Why can't she come to me first and then go to the other houses afterwards? I just leave her alone with what the arrangements are ..."

In general terms he was not dissatisfied with what the home help did. However, her advice was falling on deaf ears. Sadly he did not have the will to make his views clear to a variety of people who had made decisions for him all through his life and even more sad, for whatever reason, that those decisions were not right for him. Professional carers need to be careful when in situations where decisions need to be made for it is often easier to make the decision than ascertain the

views of the patient. It is even harder to accept that it is unwise to offer advice, even for the best of motives.

I Have Nobody

Q. "Do you think that it is important to talk to other people if you're having to make up your mind about something?"

R. I've nobody to talk to, Nurse. I haven't.

Q. You don't use your friends in that kind of way?

R. Well I don't think it's fair."

Here is an example of those who said vehemently, "I have nobody". Clearly that is how it felt to her. She did still have a brother, nephews, nieces and a fairly wide circle of friends. She is a lady who has made decisions about herself and her family all her life with little reference to anyone else. She organised a sister's funeral to be a private occasion to the dismay of other members of the family. She went to hospital to have surgery without telling her next of kin. If there had been some decision to be made about her treatment or placement at the end of her hospital stay and the hospital staff had contacted her next of kin, the whole process would have been dreadfully complicated, not to say acrimonious, and more important, not right for her.

Here is another example:

R. "Well I had no difficulty in making the decision (marriage) - (laughter) - an obvious thing. It wasn't a case of shall I or shan't I.

Q. And did you talk to other people about that?

R. No, no need. To consult them? Do you think I'm wise? What do you think of this? Oh no, no need. Anyhow it was for me to make up my mind. It was my life and nobody else could really advise me about it.

Q. And I suppose your parents were dead by then?

R. Oh yes, they were dead."

It would seem likely that where the isolated (either by choice or chance) are required to make decisions, then this situation calls for great imagination and tact but mainly a listening ability on the part of the carer. Time might be more important in these cases, though in the second instance cited this would have been untrue. It is salutary to realise, especially by nurses who are only children and therefore have faulty expectations, that siblings may not be wanted or liked, or found helpful. One tends to interpret issues from one's own perspective.

Of course there can be an obverse of that. Most of the group of those interviewed had several siblings and some had many. One lady from such a family made the point:

Q. "Now when you went there that was the first time that you'd been away from home. Did you find that very difficult?

R. Did I make my own decisions there?

Q. Yes.

R. That I was being allowed to think for myself, and just do what I wanted. Maybe it is an awful thing to say, but I just felt that I was ... that I could do and think for myself. That I really hadn't been allowed to do before.

Q. Did you talk about that to anybody?

R. No, no I had to do it all myself."

So that there are times when being alone is a positive bonus. It would be sad if nurses pressed someone to use other people in coming to decisions if, in fact, the liberty was fairly new found and being relished.

Some of the men in the group talked warmly about the camaraderie they experienced in the ward. One in particular was clearly seen as a leader because the nurses repeatedly used him to get information about how the other patients were feeling or to ascertain what was bothering them. This phenomenon which is well known, especially in male wards, might be an important means of discussing problems for those who are alone. Of course the reverse was seen. There was one man who said that he did not speak to anyone and spent the spare time when he was improving wandering the corridors of the hospital. For this last man the nurses impinged very little and any information he got he obtained from the doctors.

I Pray About It

- Q. "One of the things I am interested in is how people make up their minds about things.
- R. A lot of major decisions in life I've dealt with with what the Christian religion would call prayer. That needs a lot of definition. Prayer for me is when you want to think it out and want to talk to someone. You would discuss with your wife but we wouldn't want to go to a neighbour or somebody else, we would want to discuss it with our God. You don't do that on your knees with your hands clasped. I go into the garden, pot up some plants, get into my workshop there, and I think about it. I'm relating to some power or some being. I don't think you get immediate answers."

For two of the group this was the initial response to how they made up their minds about things. In both cases prayer

comes ahead of discussion with their wives on occasion. Both men have had a long and close involvement with the church. One was much clearer than the other that he always got an answer to his prayers. After discussion about the nature of prayer he was able to articulate that the answer for him was in the nature of an inner conviction that a certain course of action was right:

Q. "Now can you tell me how you think guidance comes?"

R. I think I don't get flashes of imaginative leading but sometimes the next day I can do whatever it is, better, but with more understanding. My wife was not well - I couldn't manage. I think the next day I was better able to manage. No magical solution but just better able to manage.

Q. When you are praying for or about something of that sort, how do you do it? Do you actually do it in words or ...?

R. No, I just sit and think about it."

The other man was much less articulate about how prayer worked, though he was less sure that he always got an answer eventually but decided that it was sometimes in a negative form. One of these men was the only one who spoke at all about using the services of the hospital chaplaincy. Sadly he met with a punctilious priest who undermined the experiences he had had in the chapel and several months after the event he was still hurt and confused.

The spiritual dimension in this overt form is very important to some people and, though probably for the majority of nurses it is not shared, it is useful to have it underlined in this research. Though all the group had some church connection, these were the only two who spoke about any aspect

of faith or doctrine that had any direct bearing on decision making. This of course does not properly reflect the moral dimension on which a great many people base decisions about themselves. Perhaps it only reflects the British reticence to talk about such issues.

I Go to the Garden

As has already been noted, the use of the garden was related to the use of prayer. One of the men reported that, after talking over the problem with his wife, he retires to the garden shed where he does some potting or woodwork. Only after time alone, ostensibly doing something else, does the deliberation come to fruition. Though it is obvious that ward staff cannot provide the garden shed, it remains that peace, quiet and a period of withdrawal are requisite for quite a lot of people. Another of the respondents made a similar point:

Q. "Did you use time in the garden for thinking about things?"

R. Oh yes. I do a lot of thinking in the garden. Sometimes I waken up early at 4 or 5 and my mind starts to go to work and by the time I've got up I've got the answer. I'm talking about practical problems, I've got the answer. It's an exhausting way of doing it. But I think some people are made that way."

Many women with young children speak of the importance of sitting in the bath as being the only place where they find solitude. This may be an important use of the bath in hospital, apart from the more traditional cleansing function. Old men often smoke their pipes in the toilet and many people are accustomed to reading books or doing crosswords there too! It

must be a great trial constantly to be harried out of the toilet or bathroom because of a queue or nurses not being tactful.

WHO MADE DECISIONS AT HOME?

Q. "When you were young who made decisions in the house?"

R. Decisions? My mother of course. She wasn't a bossy person at all but my father just didn't bother. He never bothered you although he had a tawse hanging up but he never used that, nothing like that on us. He wasn't like that ... You went to your mother and she told you what to do. We had to ask him usually afterwards but it was always she I can remember."

Almost without exception it was the mother who made the decisions. It was clear that men worked long hours and so they were not there for much of the time. Quite a number of these respondents were from large families where money was scarce and they lived in cramped conditions. It is not surprising that of necessity the women 'ruled the roost'. Even in the cases of the more comfortably off, there the men were involved in the war and so the women had no option but to make decisions.

Although the feeling represented above is overwhelming, there was also an element of not really knowing:

Q. "Who made up ... who made those sorts of decisions in your family, I mean when you were wee?"

R. God, I couldn't tell you, I never thought about it.

Q. You don't know.

R. I don't really know."

This presumably arises from decisions not being for public debate or comment. One lady has very vivid memories of the nursery, where children spent their lives until they were old enough to stay up for dinner at night and the only contact with her parents was within the formality of meal times.

None had anything to say about chastisement being meted out and certainly it was not ferocious. In one house, as we have seen, there was a leather strap hung on the back of the door, presumably as a threat only since there is no memory of its being used. Several remember never being smacked at all. In the house of the nursery the punishment was being made to run up and down the stairs of the house which was on four floors, or being banished to the pantry to finish eating. So that most of the discipline must have been in the form of mothers' speech. One of the most characterful and determined of the group remembers one of her sisters as being "bossy" and, indeed, the impression is given that it was the sister who ruled the house rather than either of the parents. Despite there being quite a number of boys in these families, there were few who were remembered as being in great need of discipline because they, along with their sisters, "knew what was right".

The curious thing about respondents with children of their own is that though they all felt that their own upbringing had been happy, orderly and greatly influenced by the moral standards of their parents, they were much less assured about

what they had handed on to their own children. Most were unwilling to talk at all about the values or commitments that their children exhibit which they can see as being inculcated by them. Very few children, for example, have retained an active church connection, though most had been exposed to Sunday School, and some to a variety of church organisations, as well as regular attendance at services. Only one man regrets that he did not spend more time with his children and wonders if he and his wife relied too much on example as the means of imbuing them with Christian standards.

HEALTH CARE DECISIONS

Several of those interviewed had used private medicine, but this mainly before the setting up of the National Health Service. Almost all the children born to those interviewed were delivered at home with the help of midwives. There were only two who had used private medicine in recent times:

Q. "Can you remember there being any difference between your present illness and your hips being done?"

R. Well I'll tell you, we are in (an insurance) and that was a different kettle of fish. You had a room to yourself. And all the staff are trained. You never get a junior nurse.

Q. Did it feel very different as a patient?

R. Yes it did indeed.

Q. Why did you go to the National Health Service this time?

R. I had no option.

Q. Because of it starting as an emergency?

R. Yes. And thinking about it I wouldn't want to go to (the private hospital) for major surgery. I'm not sure that they've got all the resources. The nurses are all trained by the NHS.

Q. The doctors too!"

It was the private room, a telephone and television that were the main reasons for going for private treatment in the case of this particular patient. Another had in the past consulted a doctor privately and indeed demanded that he come and see her one morning when there was a deterioration in her condition, this despite the fact that the doctor had retired in the interval. He duly responded and when the crisis abated convinced her to consult someone else. There have been occasions more recently when she has again consulted privately but the bulk of her hospital care has been within the public sector. Of course most of the care offered by the private sector does not lend itself to the treatment needed by elderly people. None of the group had any great problem if they were unwell; they simply contacted the general practitioner and used the NHS services as they were supplied or suggested. Those who needed the help of community nursing services had these and used them willingly and gratefully.

This does not mean that the group saw hospitals, nurses, doctors, or their services without comment or criticism. For example:

R. "And I wasn't too struck with the (a hospital).

Q. What was wrong with (----)?

R. There's nothing wrong with it. I felt some of the nurses were supercilious. Felt they were something. The old (nurse) she was all right but she went away for two or three days and I didn't have her.

Q. Yes.

R. I didn't like the way they had this sitting in a corridor ... you go along this corridor which leads you to the wards and things and that's where you sit at tables and a settee and they've got the TV stuck in the lobby, you know.

Q. How funny.

R. And then you couldn't hear for nurses shouting at each other from one end of the place to the other and dropping trays ... If I was in again and they said go to (----) I wouldn't go, I'd just come home. Some things they try to do but they were awfy sour staff. They could have been better."

There was dissatisfaction with the care given by particular doctors too. These comments related either to coolness or a problem in getting information. The main impression gained about nurses was of a busy, unknown workforce of basically kind people. But sadly there were some cases of nurses quite misunderstanding what patients wished. There was one story of a lady giving the whole sum of money that she had saved for a holiday, which she was no longer able to go on because of her medical condition, to the ward sister. The money was given to provide for simple repairs and replacements of faulty equipment. The patient had made it clear what the money was intended for. The anger and hurt that she felt when the ward sister came and asked if they might spend the money on a social outing for the staff was still acute many months after the event, presumably in part because she did not have the courage to say that she did mind.

The whole process of how patients make decisions is individualistic but there are some pointers that carers might remember with effect, such as allowing patients more time than might be thought necessary. Some will want more time; peace to think about it; some will want someone else to talk to; while others will come to a decision alone. But in terms of the present work, perhaps those who need most care and help are those who claim that they cannot make up their minds, for these are the individuals who have some impairment of autonomy of will and only if the impairment is diminished can one expect autonomy of action.

CHAPTER 6

Nursing Perspective

OVERVIEW

From the information gained from the review of the literature, together with evidence from the case studies, an analysis of the concept of autonomy as it relates to nursing practice is attempted. Some people may think that this relationship is of little importance because they will not see its relevance. This will be particularly so if autonomy is not recognised by practitioners as an aspect of their relationship with patients. It will be even more so if they do not take cognizance of the fact in their practice. Autonomy is a concept that has a profound relevance to the individual, whether a nurse, a patient, or a doctor when he is involved in the delivery of nursing care. The specific relevance to nursing will be addressed under two major headings: nursing involvement and nursing response.

INTRODUCTION

Autonomy has been described as having three dimensions: autonomy of thought; of will; and of action. Autonomy of thought is the most hidden or private aspect and it is therefore most difficult to establish when that autonomy is interfered with. Here it is maintained, however, that the most vulnerable aspect is that which refers to will. It has also been noted that when autonomy of will is reduced, then autonomy of action is necessarily affected. The dimensions of autonomy which are internalised, that is to say autonomy of thought and will, are inevitably easiest to ignore since the individual

must give some outward expression of that autonomy. These internalised dimensions of autonomy, however, can be expressed non-verbally if sufficient care is taken to ascertain the patient's thoughts and desires. In cases such as the aphasic patient following a cerebral vascular accident, the inability to speak may be interpreted by some carers as being commensurate with a failure to think. Where autonomy of thought is retained but autonomy of will impaired by the patient's condition, or ignored by the carer even if originally unimpaired, two inevitable outcomes suggest themselves. There will be either conflict between patient and carer when each takes increasingly entrenched stances, or else the patient will feel increasingly helpless. Thus ignoring expressions of autonomy of will increases the probability of this dimension of autonomy being further ignored and impaired in a vicious circle.

The life history data demonstrated that in the elderly decision making tends to be a more contemplative, and therefore longer, process needing discussion and corroboration. This indicates an inherent problem for autonomy of thought in the elderly. The consequent effect on autonomy of will bears on an aspect of patient care which is of fundamental importance - that is to say, the achievement of appropriate individualised care for each patient.

THE NURSING INVOLVEMENT

Having described a concept such as autonomy leaves the question of its relevance to nursing to be considered. This work claims that autonomy is not recognised and even sometimes taken for granted. Before it is possible to make any comment about a nursing response to autonomy it is necessary to discuss the nature of nursing.

WHAT IS NURSING?

A Definition

What nursing is, or should be, has been debated for a long time and the debate continues. There are some theorists who argue fiercely that the debate is not yet sufficiently extensive in both the range of subject matter and the range of contributors. Over the years there have been writers who have addressed the question in a variety of ways. Much of what the theorists or model builders have said is both abstruse and confusing, and the language which they apparently share is often lacking in precision.

Perhaps a reasonable definition to use as a starting point is that of Henderson (1966). Her view of the distinct role, which has found wide acceptance, states:

"The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to peaceful death) that he would perform unaided if he had the necessary strength, will, or knowledge. And to do this in such a way as to help him gain independence as rapidly as possible". (p.15)

It is perhaps noteworthy that any widely accepted definition, by the very success of the distillation of concepts, may well inhibit the consideration of the nuances of those concepts. Any definition implies that all the possibilities have been considered. At least in part, this definition might be cited as a stimulus for the further thinking and development of statements at different levels of abstraction which have followed it. Henderson did not set out to develop a theory of nursing and has insisted that her work provides no more than a statement (Marriner, 1986). Be that as it may, Henderson certainly had thought a great deal about nurses, patients, the relationship between them and the means by which that relationship achieved the goal of nursing. She identified 14 fundamental needs which are shared by all patients. These are the physical aspects such as: breathing normally; eating and drinking adequately; eliminating body wastes; movement; sleep and rest; keeping clean and maintaining temperature within normal range, and the sociopsychological aspects of the need for communicating with others in expressing emotions, needs, fears or opinions; worshipping according to one's faith; work and recreation; and, perhaps the most abstruse, the need to "learn, discover, or satisfy the curiosity that leads to normal development and health and use the available health facilities" (Henderson, 1966, p.11). In terms of this definition, the unique function of nursing is to help people to achieve these human functions. Clearly, such help is offered at different levels: firstly, as a substitute

for the patient where he cannot do things for himself; secondly, as helper to the patient to regain his independence; and thirdly, as a partner of the patient where together they will plan care. She wrote of the need for nurses to "get inside the skin" of each patient in order to know what that patient needs (Henderson, 1964, p.63).

At the heart of Henderson's (1966) definition is the idea that the function of nursing is the relationship which aids the establishment or re-establishment of the fundamental needs of individuals. The truth is that for some patients and nurses it is death and dignified giving up of these needs which requires to be accepted and striven for, a state which the definition clearly states. The function espoused by Henderson can only take place where the patient's individuality is clearly and overtly espoused.

Activities of Living

The concept of 'needs' has been distinct and fundamental to theorists of whatever hue. The identification of a framework of 'needs' as activities of living has gained favour since it most easily reflects the aspects of the individual to which nursing responds. Most commonly, 12 activities are cited, namely: maintaining a safe environment; breathing; eliminating; controlling body temperature; working and playing; sleeping; communicating; eating and drinking; personal cleansing and dressing; mobilising; expressing sexuality; dying. The similarity of this list to that drawn up by Henderson is clear. What this list omits are the more abstruse and idiosyncratic

areas of life such as expressing emotions, needs, fears or opinions, worshipping according to one's faith, satisfying curiosity. The main British proponents of this schema are Roper et al (1985). It is perhaps their very Britishness that explains the dropping of the other 'needs' identified by Henderson.

They claim that each activity has three components: physical or physiological; social; and psychological. It is easier to discern these in some of the activities than in others. Each activity of living is seen to be on a continuum of dependence to independence. No doubt one could, for example, have an interesting argument about what constitutes independent dying. The idea of independent dying raises possibilities of suicide or euthanasia, which presumes a control over dying. Though nurses do recognise that there are patients who "turn their faces to the wall", these deaths are generally found to be frustrating and leave nurses, and often relatives, with a sense of failure. It might be that it is the implied acceptance that independence, by definition, is good which raises the problem. Despite whether one agrees or not with the idea of the propriety of the dependence to independence continuum, it remains that these activities of living are the most easily recognisable aspects of humanity.

These model builders also place their lists of activities on another continuum which they call life span. For Roper et al (1985) life span starts at conception and ends with death. Curiously, the only developmental mark they place on that

continuum is birth, which may reveal an indecision within the trio about when life begins. Of course marking birth does draw attention to the status of the unborn child. In truth, however, it is somewhat irrelevant since the activities of living, as far as the foetus is concerned, operate at a quite different level and if a pregnant woman is being cared for the prime concern lies with her. The start of life, like dying, is a conundrum about which one can speculate for a long time. Perhaps the most important point to recognise is that in this model of nursing the focus of nursing activity depends very much on the physical aspects of living, and the degree to which individuals can carry such activities out independently.

Self-Care

These concepts of needs or activities of living are also fundamental in more complex theories of nursing such as Orem's (1980) work. She calls activities of living, or needs, universal self-care requisites. The self-care requisites are eight in number and enumerated as being the maintenance of air, water, food, elimination, activity and rest, solitude, social interaction, the prevention of hazards and promotion of human functioning. Though in one sense these requisites are also shared by humanity, such a way of thinking about them underlines the individuality of the person and his group and, importantly, they are met by the choice of the patient. Orem (1980) sees self-care as being:

"Learned behaviours that purposely regulate human structural integrity, functioning and human development. The theory ... denotes

the relationship between the deliberate self-care actions of mature and maturing members of social groups and their own development and functioning as well as the relationship of the continuing care of dependent family members to their functioning and development". (p.28)

The requisites are divided into three categories: the universal self-care requisites already enumerated; developmental self-care requisites which promote life and maturation, and prevent conditions which would prohibit maturing; and, finally, health deviation self-care requisites which are illness and disease, and the appropriate response to these by seeking to apply relevant medical knowledge or getting care and advice from those who have medical knowledge.

These situations of deviation are responded to by nurses in one, or a multiplicity, of three types of nursing systems. The first are by wholly compensatory nursing systems, the second, partly compensatory systems and third, supportive-educative systems. The method of assistance can be:

- "(1) acting or doing for;
- (2) guiding;
- (3) teaching;
- (4) supporting;
- (5) providing a developmental environment".

(Orem, 1980, p.61)

Clearly, in this view of nursing the emphasis is on the individual's decision and responsibility to look after himself and what happens to him. The nurse's role is very much related to attempts to make people independent, rather than doing things for individuals, which allows the patient to reassume the active role in his care. This recognises, of course, that

there will be some instances when mobility and other functions require outside intervention, often on a long-term basis.

Adoption of the radically different emphasis of patients having total responsibility for their health and welfare would be difficult because of our history, allied to long-standing views about health care being available for all, and freely available help for the needy, the weak and the impoverished. Such an emphasis, however, underpins much of the health education campaigning which has been prevalent in recent years. There might be difficulties in persuading nurses to adopt ideas of self-care wholeheartedly, but there are some specialties and areas of nursing practice which lend themselves more obviously to this stance than others. Walsh (1986) has suggested that accident and emergency work is an ideal setting for implementation of such a nursing theory, but has doubts about its applicability to long-term care of the younger patients who are chronically ill or the elderly. Such a view may reveal a misconception of the degree of autonomy which both the chronically ill and the elderly could and should exercise in relationship to their care.

It is a matter of great interest that the word 'autonomy' does not appear in the index of Orem's, 'Nursing: Concepts for Practice' (1980). There is, of course, much that tacitly demonstrates ideas intrinsic to the concept of autonomy. The patient's involvement is not overt, but rather the weight lies with the nurse's role. The nursing systems:

"... are formed when nurses use their abilities to prescribe, design, and provide nursing for legitimate patients (as individuals or groups) by performing discrete actions and systems of action. These actions or systems regulate the value of or the exercise of individuals' capabilities to engage in self-care and meet the self-care requisites of the individual therapeutically".

(Orem, 1980, p.29)

There is little or no space for demonstration of what the patient wants or feels is right for him other than his seeking medical knowledge, or getting care and advice from those who have medical knowledge. Of course 'good nursing' is not merely the nurse prescribing on what she perceives but in conjunction with the patient's wishes, and so autonomy is at the heart of Orem's ideas.

The nursing process is a problem-solving process which, by assessment of the problem and the desired outcome, and planning the appropriate response to that problem, is followed by implementation of the response and completed by assessment of the outcome. The initial assessment of a difficulty in conjunction with the desired outcome are the pillars of the process. The aim might not always be toward improvement. There may be times when there is an attempt to preserve the status quo. For example, if a patient has a progressive disease and improvement is not possible, the aim must be as far as possible to stem further deterioration. On the other hand, in the case of the long-term care of an elderly patient who is demented, the aim is improvement in such areas as are amenable. Perhaps being able to make accurate assessment of a patient's

capabilities may be one of the most important functions of a registered nurse. Failure to recognise potential can lead to loss of dignity and to dependence. To make assumptions, however, that the patient is capable of more than he is, or indeed that he is maliciously misbehaving, can lead to inappropriate care and to possible neglect which might border on the cruel.

The elements of evaluation of the problem, assessment of outcomes and the intervention are intrinsic to the personalisation of care. But to be truly satisfactory, such assessment and evaluation must reflect the relational quality of nursing between nurse and patient. Each of the already mentioned ways of explaining or defining nursing makes clear (if not overtly underlined) that the fundamental nature of nursing lies in the relationship between the nurse and patient. When both partners are active in the nursing process, then the function is a satisfactory one. To date, that relationship has been seen to focus mainly on the physical aspects of living and care, but there are other elements which have a profound influence if the patient is to be cared for as a whole person. Where there is difficulty with the relational quality of nursing, nursing tends to become a matter of doing things for and to people. Such a situation results in dependence.

Dependence

One of the facets of each of the definitions or explanations of nursing already referred to is dependence. Rodenbach (1982) has provided an exhaustive study of the

concept of dependency. From her examination of the literature the complexity of the concept is clear. She concluded that at present there is a lack of clarity, or universal applicability, of the concept of dependency and indeed that it is used interchangeably with other related concepts. Of course everyone experiences dependence, whether it is as the child being dependent on the parent or the adult dependent upon his friends. Despite its being a shared experience, there is a predominantly negative assessment of dependence. This may be because, as Rodenbach (1982) has shown, there is a correlation between dependency and conformity, submissiveness, aggression and distrust. She also notes that hospitalisation and the sick role itself increases dependency and therefore necessarily reduces independency.

Nursing is seen, then, to have a special relevance where dependence exists. It is of note that in the United Kingdom the means of devising, like the Aberdeen formula, appropriate levels of nursing staff in wards is based on the degree of physical dependence expected to be experienced by the patients who will be cared for in a particular ward or unit. Where self-care has failed, a level of dependency, almost by definition, exists and, in Orem's (1980) view, the nursing function is to urge, assist or teach the patient to re-assert independence. Henderson (1966) also quite overtly states that the nurse's function is to help patients "gain independence as rapidly as possible". The activities of living are seen as operating on a

continuum of dependence to independence, with the tacit adherence to the view that independence is obviously the 'good', or at least better, end of the continuum and therefore the one to be striven for. As has already been commented, dying independently is an interesting notion, as are the notions of expressing sexuality or communicating independently. It can reasonably be claimed that these, among other activities that are important to human beings, can only be undertaken with other people, or at least in relationship with others and often only significant others. That, however, may be carping criticism but there is an element of truth in it and it may point to something important, namely that nursing is only required when independence is not possible for patients, and when important others are not capable or available to give such help and care as is necessary. There is a certain arrogance in the assumption that if a patient cannot communicate with the nurse, he cannot communicate with anyone.

The model that nursing has operated within for most of its history has been a biomedical one. That is to say, the problems which patients have presented with have been seen in terms of diseases or maladies which medicine could cure or, as yet, did not have the required knowledge to trounce. Nurses followed in the wake of such battle and carried out the necessary treatment or the following ongoing care. Inevitably, this led to the depersonalisation of individual patients. Another aspect of such attitudes of lack of individualisation was that there was

a supposition that every patient behaved in a certain way, which led to a standardisation of care and task orientation (Pearson and Vaughn, 1986). To make this system work requires co-operative patients and preferably dependent ones. Such a view may also have answered the desire which causes very many people to choose nursing as a career, which usually is expressed as wanting to help people.

It is the soft, gently empathetic nurse who can, in fact, create dependency. She is the one who makes the patient believe that he is too ill to do things, or that someone with such a diagnosis needs to keep safe, not go out, not tax himself and generally withdraw. It is this sort of caring which makes relatives (often parents in the case of young children and children in the case of the elderly) feel that their response should be a much more prescriptive and protecting one towards their patient relatives, who might not have the power, or will or knowledge to argue.

When nurses are faced with unco-operative patients they can impose sanctions, as Stockwell (1977) has shown. These sanctions can make patients dependent, or conversely very angry and even more unco-operative. Doctors, also, are sometimes responsible for dependency in patients. Their power of knowledge, a general inaccessibility, status, and always seeming to be very busy are among the ways in which they can instil dependence (Freidson, 1970; Kenneth and Jones, 1975; Kennedy, 1983).

The environment in which people find themselves certainly contributes to dependency. Contemplation, for example, of children who are self-reliant and those who are not shows this. Children brought up in care frequently display evidence of dependence. The elderly show similar patterns. Miller (1984), after reviewing the literature, concludes that:

"Some institutional environments can produce extreme social and physical deprivation for inmates, and it is probable that some of the deterioration of old people in hospital wards is not an antecedent event which is followed by dependency, but a consequent event preceded by detrimental ward environments".

(pp.484-485)

Research has shown that patients taken from poor surroundings and placed in another where the atmosphere is more like home, where patients are referred to as residents, and where they are given much more say in what happens to them and how they spend their days often become much more independent (McIntosh, 1983).

Unfortunately, autonomy is often seen to be synonymous with independence and to some extent that is true, but it depends on what one means by independence. Clearly, if independence is defined as being physically self-reliant, and if it is in this area that nursing operates, then indeed autonomy is only applicable to those who are able-bodied and mentally fit. It has been argued in this work that that is much too fine a definition of independence and, indeed, does not hold in practice. There are examples of people who are confined to a wheelchair and yet are very independent of mind and will.

Where there is physical self-reliance, there is a degree of autonomy of action almost by definition. But despite that, there is a possibility of interference with autonomy since it does not follow that such a person will have full autonomy of will, which inevitably affects autonomy of action. Too, at a different level, it is possible to have interference with autonomy of thought which interferes with autonomy of will and necessarily interferes with autonomy of action. It is being posited here that nurses have a special role to fulfil in this area of the care of patients, namely in recognising, preserving and encouraging autonomy.

In the explanations of what nursing is, there has been a recognition that nursing is a relationship between nurses and their patients whose aim is to make patients as independent as possible. When cure is a real option, then the return to autonomy of thought, will and action will follow almost inevitably. Problems, however, arise where cure is not possible, or where cure will be long delayed. Here, helping patients to retain autonomy of thought, and even more importantly autonomy of will, is the main function of the nurse. The incomplete nature of the nursing theories already cited is in how these aspects of autonomy of will and thought fit and are addressed.

Certainly, there is no doubt that the enabling quality of nursing is most important. It is of moment that Henderson stressed the will of the patient as being vital. The nurse's main contribution is not to take over the decision making

function but to recognise and respect autonomy, and react to any evidence of interference with autonomy of thought, will or action in an attempt to tackle and solve the problem. Further, it is being suggested that nurses may find it most appropriate to tackle problems of will. In instances where the problem is insoluble, it is by detecting the real essence of the individual personality that they will ensure that decisions which have to be taken will be in sympathy with that person.

The difficulty of coming to appropriate decisions for particular individuals is no easy matter and has been well recognised. It is, in part, a response to such difficulties that it is becoming generally accepted that more than one person needs to be involved. In time past, the one person who made decisions was very likely to be the doctor. The move away from this has accepted the propriety of group decision making, which has given rise to the involvement of the team as well as the rhetoric of teamwork. Generally, the team consists completely of professionals. The medical social worker, physio-therapist, occupational therapist, doctors and nurses might meet and discuss in detail the pros and cons of a particular situation and come to a decision which is deemed to be in the best interest of the patient. The one voice that is often silent is that of the patient. There is often an assumption that the nurse will speak for the patient since she has most consistent contact. The patient, however, may have no knowledge that he is being represented, or even that his future is being discussed (Melia and Macmillan, 1983). It is an awareness of

this difficult area which has led to pleas for patient advocacy. Advocacy, however, to be effective, requires that the person being spoken for is active in making his views and feelings known to his advocate.

The group of elderly people interviewed in the present work had little or no awareness that any decisions were made. Certainly, they were sure that they were never asked or involved openly. Several of the group were sent to a different hospital for a period of convalescence, which it might reasonably be expected would have been discussed with the patient. In fact, they were merely being told that it was going to happen. Two of the group evinced a grim determination not to go back to convalescent settings. This could provoke difficulty if, on a future occasion, it is a predetermined decision which is communicated to the patient.

This does not mean that these professionals are setting out to be unkind or that they are acting in a completely wrong way. It is, of course, an example of paternalism in response to risk. The suggestion is that practice could be improved and thus care be more satisfactory for the patient. There is a desire to retain control over what happens to us, a desire shared by almost all patients, though perhaps most vociferously articulated at the present time by women involved in the obstetric and gynaecological services. Autonomy, then, has a relevance to the practice of nursing. Before any suggestion can be made as to the suitable response for nurses to adopt towards such a concept, it would be useful to ascertain whether or not

it can be recognised and, if so, then how to respond to it and encourage it.

THE NURSING RESPONSE

RECOGNITION OF AUTONOMY

Autonomy is a difficult concept to explain or discuss and it may be something that people who are physically, psychologically and socially independent (the majority of professional carers) take for granted. Because the 'normal' state is experienced by most people, the concept of autonomy is not often enunciated and therefore probably little understood. It is possibly a by-product of that lack of understanding which results in more patients' autonomy being diminished, or indeed lost, than has been realised. It may indeed explain, in part, the reason why patients feel as strange as they do when they return to the community after a hospital stay.

It is because autonomy is not understood that it is so easily ignored, especially in hospital. The life history data has shown that there are examples of ignored autonomy to be gleaned by listening to patients and understanding their explanations of what has happened to them in the past, and why they are as they are at present. Autonomy is one of the cornerstones of the concept of personhood, which is sometimes loosely described as individuality and uniqueness. Nurses and nursing, particularly in recent years, have paid increasing attention to individuality. One might therefore suppose that the intrinsic

component of autonomy would be a concept that would be recognised and seen to be important, but so far this has not happened.

Those respondents who spoke about being unable to make up their minds are probably, according to the author's framework, giving the main sign that there is a difficulty with autonomy of will. Of course any number of people can be found who, in reply to such questions as "Would you like tea or coffee?", will say "I don't mind". Such people may not be experiencing a problem; it may only be one for the questioner. On the other hand, the lack of decision may be a sign of interference with autonomy of will. If an attempt is made to clarify the apparent problem, then explanations such as having no preference or not wanting to be awkward will be given. These quite genuine attempts to co-operate or be polite would not be necessary in other situations, such as when individuals are in their own homes or in a restaurant. In such surroundings, no problem of will exists and here autonomy of thought and will would instantly provoke appropriate action.

The nurse must be able to recognise the difference between the person who has a problem and the person who is merely being polite, or wishing to conform. The individual patient's perception of hospitals, and health care in general, will have been formulated by a lifetime of experience, other people's as well as their own. If, for example, their perception of the ward sister is an authoritarian one, then uncertainty, loneliness and even fear might play a part. This may mean they

see the nurse as being the person to please rather than the reverse. This may result in the patient not being able to make up his mind. The nursing activity of exploring such a situation requires time and patience. It is so, however, that where the individual cannot make up his mind and cannot offer any explanation, then the nurse should pursue the matter rather than just make up his mind for him.

One of the assumptions that this study was based on is that autonomy, in the sense of self-determination, is a good thing. Individuals need to make up their minds about what is right for them. When older people experience illness they are very vulnerable. It is often an illness itself which provokes the demand for decisions to be made. The decisions may be whether or not treatment will be accepted; whether or not a return home is possible; whether or not such a return is possible only with external help; or whether permanent care is required. Such decisions frequently occur within the health care setting and nurses therefore have a most important role to perform.

Unpopular Patients

Stockwell (1972) underlines some of the difficulties experienced between patients and those who nurse them. There are various categories of patients whom nurses were reported as not liking, such as foreigners, those whom nurses felt to be in wards or units that are not ideally suited to their care, the mentally ill and those who had been in hospital for more than three months. Each of these characteristics can hardly be

affected by the patient, or indeed the nurse. One has to remain depressed if nurses cannot make the best of what both partners may well feel is a situation outwith their control, or indeed not turn it to good effect by finding a means of improvement in what is amenable to change. But perhaps the underlying problem is that nurses have an incomplete understanding of both themselves and their patients.

There were other categories of patients which made them unpopular to nurses which ought to have been much more readily open to change, such as patients who grumbled and complained; communicated a lack of enjoyment at being in hospital; and those who apparently were suffering more pain and discomfort than was believed proper by the nurses. From the point of view of autonomy, it is these categories which suggest that these are signs of dissonance between what is being imposed on the patients by their situation and those in control, and what the patients actually see as being appropriate for themselves. Certainly, nurses know cantankerous old people, often men, who make a relationship difficult. But it is possible that such situations can be immensely rewarding for both patient and nurse if persevered with, explored and compromises achieved. Indeed, there is often a great deal of merriment and fun in such relationships. In situations of dissonance, is it not a sad reflection on nurses and the care they offer that patients feel they must deal with their discomfort and unhappiness in such a way? Perhaps with better education, which would provide nurses with the explanation that such behaviour occurs usually

when autonomy is being challenged, or even prohibited, then change can be encouraged and improvement achieved.

Idiosyncratic Patients

The overwhelming point to remember is the individuality of patients. Nurses can make no assumptions about patients. Though much lip service is paid to the notion of individuality, it is a demanding notion to respond to. Nurses forget it at the peril of patients and the future trust within which practice will be carried out. A group of patients like the elderly is specially vulnerable; it is fairly easy to see a ward of demented elderly patients with little to separate them and therefore to standardise care by task rather than individualising care. Johnson (1971) underlines the idiosyncratic nature of patients in his novel of elderly people in a long-term care setting. They reveal their individuality, both in their pasts and in their present abilities or lack of them.

There is anecdotal material in the nursing press which indicates the idiosyncratic nature of patients. In the data there was an example of a man who described himself as being a loner. When he was able, he spent many hours walking about the corridors of the hospital on his own. He also complained that the nurses kept forgetting his requests, one of the sanctions that Stockwell (1972) suggests nurses use to attempt to draw patients into line. The patient from the sample is an interesting, well educated, thoughtful man. He struggled during his hospitalisation with very major questions about human suffering and, on a personal level, whether or not he would

accept further treatment should it be necessary. Sadly, one must accept that the nurses and a chaplain both failed him in this difficult time, though for different reasons. Perhaps it is this lost opportunity which has retarded his return to full independence.

Naturally, it must be accepted that idiosyncratic patients do demand imagination, time, patience and continuity. Continuity is one of the aspects of nursing that is under siege due to the difficulties imposed on the day-to-day care by the complexities of management. One cannot expect patients, especially older patients who do not readily fit into the usual 'identikit' patient, to build relationships with very many nurses.

In patients who have difficulties with communication, the demands on the nurses to recognise autonomy are heavy. For these patients, it is well worth struggling with. Such patients sometimes cry in frustration; give up speaking at all; bang the table; exhibit angry responses; withdraw; or become depressed. Often relatives or friends can help in the explanation of particular behaviour and sometimes can even help with the solving of the problem. This is another area where more than one group may have a role in helping sort out the difficulties, and again time and patience are essential. It is so easy for nurses to find it hard to cope with patients who are not well-behaved and so the patient finds himself in a dreadful 'Catch-22' situation, which ends in total withdrawal.

The patients who are verbally able and can hear are at a distinct advantage. Those whose condition robs them of mobility can have verbal acuity and so, by being awkward, provoke some action. These, too, however, have to rely on thinking and patient nurses who will do things for them, move them to where they want to be, and generally accede to their requests. For those patients who have limited, or no mobility, and a speech defect, or cannot hear or are blind, the problems of communicating what they want, need or would bring comfort demands not only a recognition of their suspect autonomy but also a determination on the part of nurses to try to protect it.

Decision Making

The data show that elderly people take longer to make up their minds about things, so that if a patient needs to come to some decision about some matter, then that process will probably have to be given a longer period than might normally be thought necessary. This would indicate that if an elderly patient is thinking about something, then probably autonomy is being exercised. By the same token, if a discussion is taking place, then the possibility is that the process of practising autonomy has been entered into perhaps with family members or friends.

Information is a necessary prerequisite for decision making and so if a patient asks lots of questions, then this is a sign that autonomy is being exercised. It might be that the

same questions will be asked several times over, or of different people, and that might well be an important means of gaining the required knowledge or just corroborative evidence. Sometimes it is not a question that is asked; rather it is that advice is being sought. When this happens a very important sign is being given that there may be a problem. One explanation may be that the person does not have sufficient information. On the other hand, it might be that so much information has been given that the individual cannot marshal all the facts, and what is really being sought is someone to pose the right questions or recite the arguments for and against the proposition.

The need to withdraw to think things out was spoken of as being important. So that if a patient who is normally gregarious, who says, for example, "I'll have to speak about that to my lawyer", then the likelihood is that the patient is involved in the practice of autonomy. The nurse's role may only be to wait and protect the silence.

Recognition in the Professional and the Patient

Much has been and is being written about the professional autonomy of the nurse. Most of the debate is related to professionalisation and the moral dilemmas which result from the practice of autonomy. One of the areas where such difficulties present themselves is that of communication of information. Nurses find patients who ask questions difficult to deal with, partly because of their professional interaction with the medical profession. After all, it is the doctor who has ultimate responsibility for the diagnosis and treatment of

the patient. It is possible for the doctors to keep patients in the dark by limiting information. But the nurse's role is more difficult since she has constant contact with the patient and may know what has been shared; or what should be divulged; or withheld; and, in any case, she might not agree with the decision made. In this situation, there are several people involved; there is the doctor, the nurse, the patient and often a relative, and each has autonomy. Here, then, is an example of where there are conflicting opinions and convictions as to what is the right thing to do. Whose autonomy holds precedence or sway? There is no easy answer when it is a case of one professional's autonomy against another professional's autonomy. The debate has been hot and long, and probably will continue for some time. It is probably easier if the patient is compos mentis and can ask difficult questions, and so relieve the "log jam" and in fact give a vicarious victory to one side or the other.

It must always be remembered that though one view was right on one occasion, it does not mean that it will be right on the next. Where the patient cannot help by being an active participant in the debate, more responsibility falls to the nurse because she will have opportunity to 'know' the patient, either directly or by other means. Too, she may have to carry out a particular plan which may well be at odds with her own view. But she may accede to the decision in the knowledge that it seems to be the best thing for that particular patient, on that particular occasion. There may be times when the nurse has

the difficult responsibility of acceding to the patient's view, as opposed to that of the relatives. This can be important in the case of children who do not want to have some procedure carried out while the guardian may wish it. It might well be unwise to take such a decision singly. The better course might be to have talked at least to doctors or other nurses about the matter.

In the present work there has been a plea for recognition and nurturing of the patient's autonomy. This is not seen as simple and the possibility of conflict is not denied. It is entirely possible for patient and nurse to be of opposing views. In some cases it is easier to resolve than in others. Whose autonomy should claim the greater benefit of respect if an elderly lady wants to return home while the nurse feels that it is not safe for her to do so? What about the slightly confused, forgetful lady who wants to make herself tea and forgets to put the water into the kettle but puts it into the cup and puts that directly onto the gas? Not only is she putting herself at risk, but she might be jeopardising a whole tenement full of neighbours. Is it all right to allow an unsteady old man to return home, with the distinct possibility of falling, rather than keeping him in hospital? Is it proper to accept the patient's refusal of antibiotics for a chest infection? For some nurses, a divergence of views with such a patient might be particularly difficult. The present work leans to respecting the autonomy of the patient rather than the professional's autonomy which may deny autonomy to the patient

altogether. But, ultimately, one has to accept that there is no easy or constant answer. It must be a matter for individual thinking and struggling in each case.

One of the most constructive and hopeful aspects in the debate about whose autonomy should receive the greater amount of respect is the realisation that individuals are not isolated. It is only in interaction with other people that discovery is made. Such a view holds, too, for an individual attempting to work out what is the right thing to do for himself. It is by giving as much information as possible, and in the light of other people's views as well as the total context of the individual's life, that decisions can be reached. Despite the perception and experience of those who claim they are alone, have no one, and never consult anyone, the claim is not entirely true for the majority. It is not being suggested that they are lying, but it remains that in fact they are not always as isolated as they feel or seem. All knowledge is gleaned either from one another or communally. The baby learns about food supply, warmth and love from its mother. It learns about the quality of mother love from sharing experiences with its peers, with their experiences. Even very strongly held beliefs of a moral or religious nature are not come by or accepted in isolation. They are gained by a teaching of other people, as well as by encountering experiences of groups, or nations; from the media; or history. These ideas are then matched or placed beside internal views. The patient might, then, come to conviction, or assurance, or decision by

talking to a nurse or simply by having arguments marshalled, or more likely by having the relevant questions posed.

One of the possible inhibitions in helping patients in this kind of way might be that there is a tendency to assume that the people we meet are like us, that their minds work in the same way, and therefore they will come to the same conclusions. Though it is possible to achieve such equilibrium in our social lives, it very often is not possible in our working lives. Perhaps this is why, in a work setting, we rarely discuss controversial topics like religion or politics. Certainly, patients are a very mixed group; some will be from backgrounds quite alien to the nurse's with values and views which cannot be predicted. It is of relevance to point out here that the International Council of Nurses (1953) states in the preamble to their code for nurses, amongst other things, that:

"The need for nursing is universal. Inherent in nursing is respect for life, dignity and rights of man. It is unrestricted by considerations of nationality, race, creed, colour, age, sex, politics or social status". (p.1)

It means, then, that bravery may be needed to explore matters based on different values or ideas with patients and colleagues. But, more importantly, it must be remembered that it is perfectly possible to disagree profoundly on particular matters but yet to like one another, to respect the differences while maintaining contact, and indeed to learn and continue to enable patients to make hard decisions that are right for them. If this is going to be done with patients, nurses have to make themselves vulnerable, in the sense of being open with and to

patients, and willing to follow their thoughts in the light of their values and not attempt to impose a personal view. This means that nurses are not being called on to change their view with every new one that presents itself, but remain very sympathetic and listen to other views. From this privileged position nurses can learn as much if not more than the patients.

VALUING AUTONOMY

One of the most potent fears that most people share is that of losing the ability to reason and thus lose control of oneself and one's surroundings. Old age often brings with it a diminution of ability in amassing and organising information, which makes coming to decisions extremely difficult. Illness, too, often affects abilities in this realm, even if not in a permanent way. When old age is compounded by illness, then the possibilities of the difficulties becoming permanent are greatly increased. Sometimes decisions made at this sort of time are greatly regretted later when the period of illness has passed and a re-assertion of autonomy of action is possible but cannot be retrieved. In the framework of dimensions of autonomy it is posited that autonomy of action rests on autonomy of will which, in turn, is underpinned by autonomy of thought. It would seem, then, that in instances where ageing has made the thought processes a problem and where illness is superimposed, a conscious effort is needed to protect autonomy of thought and will and see them as being important.

Much has already been said about individualised care of patients coupled with the intrinsic relational quality of nursing. Perhaps this is the most fundamental way in which valuing autonomy can be shown. When a nurse recognises a patient as an individual, inevitably the uniqueness of that person is being valued. Part of how one knows the uniqueness of the person is in the way he brings into coalescence what is going on around him and his personal ideas and beliefs. Nurses are in a privileged position to make that process of alignment as easy as possible.

The way in which new patients are greeted is one of the simple, and yet profoundly important, ways in which the scene of care is set and assurance given to patients that they matter. How nurses address a patient can matter as to the degree to which he fits in and feels comfortable. Younger generations find it easy to use familiar forms of address to each other, while older generations often feel more comfortable with a formalised mode. There are plenty of examples of older people who have known each other for many years on a quite intimate level and yet never use Christian names. To allow the patient to decide, and even dictate, what he will be called is a tacit assurance that he is still his own person and no one is trying to reduce him either to the level of the nameless 'Pop' or of the little girl who had no expectation of decision making.

Where a patient is experiencing some difficulty in making decisions, the means of valuing autonomy is to exercise patience and wait. It is tempting to impose a view when the answer appears easy to the outsider, but this is a very damaging thing to do. The hurt and feeling of inadequacy engendered by not having kept control long enough to come to a decision is huge. Too, having once relinquished control, it takes increased bravery to make a renewed effort to regain it or not let go the next time. If this is repeated, there can be a cumulative effect which diminishes autonomy of will most effectively and can eventually create dependence in individuals, as Lieberman et al (1969; 1971) have shown.

Another evidence of valuing autonomy is in the amount of information given and the means by which it is shared. In theory, this is perhaps the easiest thing to help patients achieve. Of course, there are inherent problems arising from a medical decision to withhold information. It might be that the nurse can act as the mouthpiece or 'translator' for the patient in his presence. Such a situation would put the doctor at a disadvantage by his being outnumbered. This might exacerbate an already fraught situation between medical and nursing staff, and therefore can only be entered into with caution. But not all nursing practice takes place in an air of confrontation and it may be that the patient needs to have some matter made clear or enlarged upon, which can simply be acceded to. Even here, however, a mistaken awareness of the patient's intelligence or lack of respect for his autonomy could cloud the amount or type of information given by the nurse.

The other facet of this difficult area is the condition of the patient. It is easy to assume that what the patient needs, wants and can use is as much information as can possibly be given. It must, however, be remembered that when patients are shocked, in great pain, or very frightened, it is all too easy to blind or confuse them with too much information. Indeed the wrong sort or quantity of information can merely exacerbate their shock or fear. Nurses have to be very sensitive because in such situations it is very easy for patients to say "Whatever you think", not because they feel that that is right for them but because by acquiescing they have relieved one pressure. Some of the interviews revealed clearly how difficult it is to deal with pain and shock while making decisions at the same time.

There are many people, as the data have shown, who turn to someone else, or a variety of people, when discussion of a problem is to be undertaken. It would be arrogant indeed for nurses to assume that they were necessarily the right people to enter into all discussion. Often patients turn to family or friends for these discussions. Making it easy for such conversations to occur might well be the nurses' means of valuing the autonomy of the patient. Too, it must be remembered that nurses must be circumspect as to which visitors they draw into decision making. Being an intimate member of a family does not necessarily mean that inherently that person is appropriate. Even the very elderly have interesting liaisons and it might be that the legal next of kin is not the person

most intimately involved. Nurses have to handle such situations with great care, sensitivity and compassion.

Often, for decisions to be made, or for discussions to happen satisfactorily, there is a need for peace and quiet, as well as privacy. The data showed that people need and use privacy in their own homes. Certainly, when wrestling with a difficult decision one needs peace and in a busy ward it is probably hardest to come by but by drawing screens round the bed space a sense of privacy is secured and could be an option offered more often. Screens, however, are not soundproof and some other space might need to be given. Relatives have commented that they have had problems with corridors being used for interviews, consultations or admissions. For the elderly patient who has lived alone for years the reality of having nowhere to withdraw to may be one of the hardest things to endure. The difficulty of how people cope with their loss of privacy in toilets and baths, as well as impervious bed spaces, is real. There is a tendency to accept too readily that one leaves one's modesty at the front door of a hospital. While, of course, there are situations when patients do have to relinquish some privacy, it is an area in which nurses could more readily demonstrate the value they give to autonomy.

When patients make decisions for themselves nurses need to take cognisance of the fact. It has already been noted that there are occasions when patients accept the nurse's evaluation of their condition or ability. The sympathy that is offered to patients can have a barbed effect. It can make the patient feel

worse than he might and so interfere with his will. By ignoring will, nurses can make patients feel worse and so more dependent. A similar effect is produced by patients being encouraged or forced to suppress autonomy. A patient's autonomy of will can be diminished by well-intentioned nurses taking over the decision making or, worse, constantly doubting what the patient has decided for himself. If the patient is very ill, tired or slightly confused, having decisions constantly challenged is enormously draining and almost inevitably leads to withdrawal.

Despite the need not to challenge decisions constantly, the converse of that must be noticed; namely, that any decision or judgement of autonomy must be provisional. Autonomy is not fixed. Even the most autonomous old lady has moments of doubt, fear, or tiredness, and therefore her decisions will alter. She may have no will to do a washing today though she has decided that her sheets need to be cleaned, but after a rest she may have restored autonomy of will, which produces action. Also, autonomy changes because people change; they develop, their thinking continues and in the light of further consideration their decision may change. For nurses, this lack of permanence is important. It means, for example, that if a patient says "I will never have another operation", that does not give licence not to re-explore that decision should the situation arise again. Of course, equally it does not mean that all individuals will necessarily change their minds in different circumstances, or even in similar ones. This impermanence of decisions is one

of the areas on which the debate about euthanasia hinges (Glover, 1977). The material produced by those advocating a living will lays stress on when the decision was made. If one makes a statement about not wishing to have one's life prolonged in certain circumstances, how can those who are making decisions at that point actually know that one's view has not changed? Certainly, it is a potentially difficult question and that is one of the defences which would be used in opposition.

Ultimately, then, the main things to be remembered are that in valuing autonomy there is need to pay special attention to the reasoning and intention producing the aspects of decision making. These are often easiest to ignore and they are especially endangered where the patient has problems with communication. The confused elderly are especially at risk, since it is often assumed that confusion is a constant state and that therefore such patients will not notice if their requests are not adhered to, or worse, if they are not asked what they would like to happen. If one is not asked what one wishes, it becomes harder to remain in touch with reality in one's own terms. The other area that must be given special thought are the vulnerable groups. There is a tendency not to persevere with the elderly; the confused; the mentally handicapped; the immobile; children; or the psychiatrically ill. In a report on medical research in children (Nicholson, 1986), it is suggested that the assent of the child should be sought if he is seven or over, as well as that of his parents

or guardian. Now there could be debate as to whether or not that is the right age or not, but at least it is evidence of valuing the autonomy of the child as well as the adults involved.

ENCOURAGEMENT OF AUTONOMY

The themes extracted from the case histories outlined in Chapter 5 draw attention to the idiosyncratic nature of people and how they make up their minds. This inevitably reiterates the call for individualised care. If the individual patient is not heeded and accepted as such, there is no hope that his autonomy will be recognised, respected or encouraged if it is being challenged. The whole idea of autonomy is about the individual nature of people and so the ideas are inextricably bound. To value autonomy it is necessary to value the person, even if there is not approval or agreement with all the things he has decided as being right for him. It is respect for the person which must be at the base of our care for patients and only that individual is sufficiently cognisant of all his history to be able to know what is right, consistent and appropriate for him. It is only by accepting patients as individual people that nurses can, in fact, ultimately nurse in Henderson's terms.

One of the ways in which this question has been addressed is by drawing up a patient profile, which outlines the plan of care for the individual, as the basis of the nursing process. The profile, as it is presently conceived, attempts to obtain

information which the nurse feels enables her to treat the patient as an individual. The type of information sought most relates to physical needs, like how many pillows are used or whether there are stairs between the bathroom and bedroom at home. Why all the information is sought is not clear to patients and possibly not always to nurses. Some of the areas are a checklist for the benefit of being a good hostess, while others encroach on the realm of information needed to deal with potential risk. Of course, argument can be made for having information about particular preferences in long-term units to help patients feel at home.

The one area where there seems to be a gap is in the realm of the mind. It is of interest to look at Roper's (1976) work on the 'Clinical Experience in Nurse Education' where she shows a patient profile which underlines this point. Certainly there is much emphasis on physical dependency and the effort is to return patients to independence as quickly as possible. There is one section suggesting a long checklist covering patients' behaviour, but there is not space or other opportunity to indicate why the particular item is selected other than as a response to illness, and there are possible explanations as to why patients may be behaving in a particular way. In the subsequent work by Roper et al (1985), there is still a dearth of opportunity to draw attention to this very difficult dimension of individuals' living.

Farmer (1985) comments that a very high proportion of needs recorded by nurses were functional needs associated with

activities of daily living. She goes on to suggest that nurses seem to be unable to identify psychological or social needs. This is alarming; the present work suggests that this inability is because nurses have not recognised the importance and relevance of autonomy, combined with the fact that the patient profile does not make it clear that this is a dimension that is worthy of note. For it must be accepted that if nurses are accustomed to using the patient profile as a checklist rather than as an aide memoire, then it is not surprising if seemingly extraneous information is not included. As the document stands at present there is no mechanism available for noting a diminution of autonomy of will. The present work has suggested that this is one area with which nurses could usefully offer help to patients as a means of encouraging autonomy. If the patient has retained autonomy of thought but has diminished autonomy of will, then it ought to be possible for nurses to explore what is the cause of the diminution and thus protect autonomy of action as far as possible.

The data provided examples of diminution because of pain, illness compounded by a domineering husband, and domination by the past, as well as the results of illness being exacerbated by a wife who stopped her husband making even the simplest decisions. In each case that impairment was related to autonomy of will resulting in diminution of autonomy of action. It would seem to be a distinct possibility that a nurse would have been an ideal person to explore these areas with the individuals and

either provide help directly or procure it. It should be possible to control pain, or to encourage the spouses by support, and so restore the patient to his accustomed role and autonomy. The other example of being dominated by the past is possibly more difficult. Unfinished business with those who are already dead can be hard to help, but often talking about it, or venting one's spleen to a sympathetic listener, and generally unloading onto someone else can produce enormous release. Such actions would restore autonomy of will to something like its full capacity and secure autonomy of action.

One of the recurrent themes in this work has been the need for information and, indeed, as a means of encouraging autonomy it is again relevant. Often the important thing that nurses can do with regard to giving information is to make sure that the patient understands all the various aspects that are required to make a decision. The other thing that is needed is to remain encouraging and supportive in the assurance that a decision is, in fact, possible and that the patient is perfectly capable of making it. Of course, the data showed that the elderly seem to be likely to take longer than younger people to come to decision and must not be rushed.

When speaking to patients it ought to be possible to find out what is important to them. They may have different principles or values to the nurse and, since it is important to be able to base decisions on such foundations, these are vital in such a process. Such information might also reveal that the nurse is not the right person to provide help in what can be a

lengthy process but, being cognisant of such information, an appropriate person should be possible to find.

In any attempt to help encourage autonomy there is a need to help people with their communication skills. It is, after all, very difficult to retain control over what happens to one, even on the level of whether one has rice pudding or ice cream, if one cannot speak or write. Nurses, of course, in such a situation must be patient and try and find out. It may be a matter of offering both dishes, making the choice obvious and awaiting a clear response, and verifying it after the decision has been made. In such situations it is not enough to ask the relatives, "Does she like ice cream?", and then give no choice. Everyone can get too much of a good thing and food is a frequent source of irritation to patients.

Nurses can also encourage autonomy by educating patients and their relatives that it is proper to ask for things. The feeling that it is wrong to ask for anything must be dispelled, though there are those who say that this is not a problem for the younger patients. Even if that is so, there is a problem for many elderly people. It may arise, perhaps, from a feeling of inferiority and gratefulness that nurses often seem to engender. Although it is a National Health Service, it is not a charity and patients, whoever they are, have paid for the service and, even if they had not paid, it is the nurses' task to help them be as well as they can be as soon as possible. Of course, the obverse of that coin is that if people make reasonable requests, every attempt must be made to meet them.

Obviously there are things that some patients might request which it is not possible to provide. But nurses are curiously careless about saying "Oh yes, I'll do that" and never getting around to doing it. One of the ladies interviewed for this study wears a wig. When she knew that she was to go to theatre the following day she called a young nurse and asked if he would be on duty the following day. When this was affirmed, she told the nurse that she would manage her wig before theatre but asked if he would be so kind as to put it back on for her before she was fully conscious so that the other patients would not know. The nurse promised to do so. Sadly, the nurse forgot and the patient recovered from the anaesthetic with a distinctly uncomfortable feeling. After a struggle, she worked out that her wig had been put on by someone back-to-front. The patient then had to ask for the screens to be pulled so that she could re-arrange it. The nurse came in the following day, full of apologies and giggles, saying that he had forgotten. There, then, is an example of an elderly lady who was trying hard to keep her autonomy but, sadly, the attempt was not aided by the nurse who had been specifically asked.

On a seemingly lowly level, it is a means of encouraging individuality and autonomy if, in long-stay units, great care is taken to allow patients to wear their own clothes and choose what they will wear on a given day. It may take longer than deciding for the patients but it is the sort of choice everyone makes and should be retained for as long as possible. It is

degrading and not respecting of the person to be dressed from a common pool of clothes. Despite inherent problems where there is incontinence or food not being properly managed, care and time should be taken to keep patients clean and tidy, and suitably dressed in their own clothes. Another of the people interviewed remembers with great irritation not being allowed to wear her own night-clothes when she was in hospital. She has no memory of any reason being given for this practice. Of course, nurses alone cannot always ensure such a situation. Where there is not access to washing machines, spin dryers and the like, the mechanics of providing a suitable laundry service can be difficult. This is an area in which nurses could act as the patient's champion when resources are being allocated. It can also be a problem if the patient does not have a sufficiently large wardrobe to allow things to be away for a period of time. Too, some patients, when they go into long-term care, change shape, either because their diet has improved dramatically and so put on weight or, conversely, the condition which necessitated the hospitalisation is one that results in loss of weight. There is something very sad about seeing a patient with clothes hanging loosely on a gaunt frame.

The means of encouraging autonomy of action is possibly most clearly seen with contemplation of the stroke patient. These patients can be reassured that they still have choice and abilities, and that if they persevere with activity they can regain mobility. If total recovery is not possible, then they can be taught how to replace a particular function by other

means. Even in the most extreme cases it is vital, that these patients are assured that they are still people; are important; that they still have choices; and that they will be given every help and support through what might be a long, difficult time. Many nurses find looking after such patients, especially if they are liable or have speech difficulties, very trying. Here, the contention is that if their autonomy of thought and will is nurtured, then the patients will be much happier in themselves, much more interesting to look after and their recovery will be hastened.

In the case of immobility there must be encouragement of what action is still possible, on whatever level. Where the immobility will remain, it needs to be pointed out that it is proper to use other people as one's 'hands and feet'; to use 'possums' or whatever other gadgetry is appropriate. Sometimes the most helpful way of securing this help is by putting the patient in touch with some disabled person who has adapted and leads a full and fulfilled life.

Sometimes it is merely a matter of simple education; for example, even very elderly people can be taught to manage catheters, stomas, regular enemas and daily injections. Of course, it might take time, patience and much support, but all that is being a nurse in Henderson's terms or fulfilling the ideas in Orem's theory. Too, it is often a matter of convincing a relative or carer that all these things are possible and that doing things for the patient is, in fact, keeping them patients, or worse, returning them to a state akin to childhood that has no chance of adulthood to follow.

In some instances, the nurse will have to support and continue the work of other professionals in the health care team; for example, the physiotherapist. Often, nurses make the task of other staff difficult because they do not follow the regime, or they do not persevere, or simply that they do not encourage. Patients, then, can lean on the person who does not challenge them and so never develop their full potential. A similar sort of support for the occupational therapist can be the difference between the elderly lady being put into long-term care and being able to return home. Equally, if the work of the speech therapist is not supported, the patient may never achieve full skill in making their autonomy known.

McIntosh (1983) has shown that a great deal of reward is to be gained from flexibility in the structure of the patient day, though this is perhaps easier to achieve in the long-term setting exemplified by the research. There is, however, still need to think about it in the acute setting. Older people, like others of any age, need those who are near and dear to them around to help maintain contact with their ordinary lives, for it is in that context that any decisions have to fit in with. Visitors are the life-blood of any sane hospital stay and so there needs to be as much flexibility as possible. It might well be that major alterations can be made in routine; for example, eye treatments might be done at 8.00 p.m. instead of 4.00 p.m. It may be, too, that if special or important decisions have to be made, for example, where an elderly patient has to decide where he is going to live in the long

term, that a special dispensation might be granted to allow visitors to be involved in a longer and more leisurely discussion of the issues.

Another area where nurses have a vital role in encouraging autonomy is in the teaching and support of those who have problems of psychomotor skills, as well as providing the imaginative aids. If a patient is constantly having difficulty in identifying his bed or the toilet, then inevitably there will be a decrease in the amount that he is prepared to tackle or to do. This, in turn, makes it easier for nurses to assume that such patients are more disabled than they really are. It is very sad that at a time of stringency there may be less available for such things as huge signs in different colours of paint to help identify doors, or different linoleums to mark separate parts of the ward area. One simple thing that, sadly, is sometimes overlooked is making sure that the locker is on the right side of the patient. Since it is impossible to reach and retrieve something with an arm that does not function properly because of disability or an infusion, or if one's eyesight is defective on one side, this simple solution encourages autonomy.

PRACTICE OF AUTONOMY

When patients practice autonomy, relatives, friends and nurses alike all need to recognise it and encourage it. It is by practice that one develops skills. Sometimes, when patients have been in hospital or ill at home, then the return to their

full level of autonomy of action can take a surprisingly long time. Perseverance is important and with technology or learned skills, then autonomy of action can be reasserted. Rehabilitation is a complex task that takes many skills, as well as patience and support. Asking others is the only means to achieve autonomy of action for those for whom rehabilitation is not an option. That demands a response from others in terms of resources and commitment to carrying out requests. The carers, either nursing or lay, need to guard against the 'Does he take sugar?' syndrome. In other words, the autonomy of thought and will must not be challenged; rather all decisions of the patient must be listened to and, where possible, acceded to.

In the case of nurses, there is practice of their own autonomy, both professional and personal. It has been noted that the nurse's views may differ from other people's, colleagues and patients alike. There is no harm in being perfectly open with patients and telling them that a particular decision is not one that the nurse could imagine herself taking, and therefore a fuller discussion with someone else might prove more fruitful. An inadequacy must be admitted since each nurse cannot be the right person for everyone. Nurses are none the worse for knowing their limitations.

Professional autonomy, too, is an area that is not without difficulty. When speaking of such a large workforce, it would be extremely strange if everyone within it agreed absolutely on all subjects. That does not, however, allow nurses to consider

that what they think is always right; rather they have to listen to what others are saying and think about the issues. If an individual does not agree, then she should argue and try and persuade her colleagues.

Autonomy, then, is a concept that is significant in practice. It is important to patients if they are going to remain individuals. It is important if nurses are going to be able to fulfil their function of helping patients regain their coherence as whole people. But, ultimately, it is not a nebulous ideal. It is a concept that, if broken into its constituent parts of thought, will and action, can be recognised, valued, nurtured and practised by patients and nurses in partnership to the benefit of nursing care.

CHAPTER 7

Summary, Conclusions and Recommendations

SUMMARY

Self-determination has been a topic explored by philosophers and theologians from time immemorial. Inevitably emphasis has been placed on different aspects in different periods. Sometimes the particular emphasis was the result of the political or religious interest at the time. On occasion, however, the stress was dictated by the life history and personal experience of the writer. The aspects of autonomy which have been consistently important have included: the power to reason; the freedom to choose; and the ability to act on the basis of deliberation. An analysis of the literature resulted in the postulation that autonomy has three dimensions, namely: autonomy of thought; autonomy of will; and autonomy of action. This work suggests that these dimensions do not operate equally but in an hierarchical fashion. These dimensions and their relationship have been shown diagrammatically in Figure 3 on page 102. The diagram shows autonomy of thought at the base, autonomy of will next and, finally, autonomy of action. Autonomy is shown not only to have a hierarchical relationship but a functional one too. There are possible points of interference indicated. The points of interference are important since where there is no autonomy of thought, autonomy of will cannot possibly exist and it follows necessarily that there can be no autonomy of action. When autonomy of thought exists, then autonomy of will might be interfered with, which results in an inhibition of autonomy of action. Obviously there are some situations which preclude autonomy of action. In such

cases there might well be no interference at all with the preceding dimensions of will and thought. This model was used as the means by which the analysis of the life histories was carried out.

The elderly constitute an increasing number of those who come within the concern of health care. Despite much research being conducted on the elderly, there has been none which has studied specifically how elderly individuals make decisions which affect their lives and health. This seems a pity since it is in the latter years that people have a wealth of experience to comment upon and there is much to be learned which can help the care of the successors. By the time individuals reach advanced years they are able to compare current decision-making with what had been their pattern previously and so give indications about the ageing process.

The method used to gain information about how decisions have been made was the topical life history method. This method was considered the most appropriate because there was a desire to compare past experience with the present. Life review and reminiscence work now has a respectable history and is seen to have a considerable therapeutic value, so that this research could be seen to have a two-fold potential for benefit to the sample population. Such a method also reveals the individuality of people. Nursing as a discipline has made attempts to promote respect for patients in their individuality but there is still

much to be achieved, especially in situations which lend themselves to domination by routine, lack of staff and facilities. The implementation of nursing process and the individualised patient profile as a basis for the planning of care are sincere attempts in the direction of personalising care. It is in the area of the patient profile that particular problems of autonomy of will may be highlighted and if such problems could be explored and solved, then autonomy of will and autonomy of action might be restored. The community nurse who has a monitoring brief on the elderly people who are potential patients of a particular general practice may have opportunity to provide the same sort of individualised care. Henderson (1966) defined the function of nursing as that of assisting:

"... the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to peaceful death) that he would perform unaided if he had the necessary strength, will, or knowledge. And to do this in such a way as to help him gain independence as rapidly as possible". (p.15)

Such a definition makes clear the need for nurses to respect patients individually and within the patients' own terms which are outward evidence of autonomy.

The professional nurse is one who practices understanding the basis on which that practice is founded. The calls for individualised care have not been merely platitudes but arise from a moral justification for nursing. Amongst other possibilities it has been suggested that justice, beneficence and respect for persons are the primary principles on which to

base care of people. Further, of those three principles, respect for persons seems to provide the most sound and embracing basis on which nursing care can be carried out. Henderson's work inherently emphasises the importance of respecting people as people which takes into account their decisions and giving care planned on the basis of those decisions.

The branch of philosophy which deals with behaviour and the justification for doing things or not doing things is that branch which we call ethics. In time past the ethics component of nursing curricula centred around etiquette and care of the dying. This has resulted in nurses being unaccustomed to thinking conceptually. The rise of a concern to be a responsible profession has brought change to the place of ethics in curricula. There are now very many nurses who call for increased authority in making accountable decisions while realising that they must also accept the inevitable responsibility. Of course this means that more nurses find themselves facing moral dilemmas in their practice and that can be a new and perplexing experience. Autonomy as a professional concern, then, is of increasing importance to nurses as individuals. Campbell (1984) has autonomy as a recurrent, if tacit, theme in his book 'Moderated Love'. He points out that autonomy is one of the marks of a profession and one by which it gains power. Studying the caring professions of medicine, nursing and social work leads him to the view that the concept

of autonomy is important to each profession, though differently. More importantly, however, he underlines that only if patients or clients have their autonomy acknowledged and acceded to will care be properly provided. The problems raised by patients expressing autonomy has drawn nurses into debate surrounding patient advocacy and whether or not nurses should or can act in this role. The concept has tangible implications for nurses and those for whom they care since autonomy of the professional and that of the patient are inextricably bound together.

CONCLUSIONS

Though autonomy is an abstract concept, this significant ethical component of respect for persons can be operationalised through the lives of people in particular cultures. When people come within the orbit of health care, autonomy, in each of its dimensions, can be vulnerable. After analysing the life histories of elderly people, using the author's theoretical model of dimensions of autonomy, it was clear that the dimension of autonomy of will was perhaps most vulnerable. When that dimension is interfered with there is the potential of synergistic interference with autonomy of action. There were some examples where autonomy of thought had also been affected. This was especially so in emergency situations when decisions had to be made about whether or not surgical intervention would be acceded to.

The data revealed that respondents were able to pick out differences in the patterns of their decision-making in their youth compared with those experienced in more advanced years. They were, for example, aware of decisions taking longer to arrive at and that it becomes more difficult to make a decision at all, even for those whose careers had involved much independent personal or professional decision-making. Old age is the time when it is increasingly likely that decisions will have to be made as the result of increasing frailty, illness or disability. Indeed, sometimes, it is at this point in life that there is a host of decisions of a major nature which require to be dealt with. This experience is possibly only matched by the period of early adulthood when a variety of decisions are demanded, such as career choices, where to live, marriage and starting children. One of the important and interesting results evident from rehearsing life stories is that the reasons for coming to a negative decision rather than a positive one are easier to remember. The overwhelming evidence in the life histories highlights the individuality of people. There were those who made few, if any, plans for the future, while others in the group had made moves into accommodation in advance of any crises. The data revealed that educational background, familial experience and career had little, if any, influence on how people came to decisions. Perhaps too, poignantly, there is an inevitable inconsistent element in that even the most strong and apparently resolute among the group will have periods of doubt and fear, and therefore will find making a decision unusually hard.

The group represented a range of people from those who very much allowed things to happen to those who struggled with decisions. It is the latter group who had most problems in hospital experience. The 'otherness' of some of these patients made them hard for nurses to deal with and some were ignored. It is not being suggested that this was malicious, but rather that the behaviour arose from a discomfort that people experience when dealing with others who are different from themselves.

Ethics is the branch of philosophy which raises questions of accountability and responsibility in practice. In this work it has been suggested that autonomy and respecting it is part of the responsibility of the professional nurse, and necessarily the neglect of such a responsibility will result in being called to account. Improvement, or perhaps extension, of ethics teaching for nurses would not only address the basic values of what it means to be a professional but could also give nurses a security in discussing fundamental truths on which people base their thinking and arrive at decisions. Generally, we assume that all people think like ourselves; but, if nurses are going to assist patients when discussions are being conducted, nurses must have security in their own views to have freedom to 'get inside the skin' of the patient and hear what he says. Sadly, one of the conclusions to be drawn from the data was that nurses appear insensitive to autonomy in patients and its implications in decision-making. Since the exercise of autonomy is important to all people, nurses have a

special role to play in recognising, encouraging and helping patients realise autonomy in their lives. Patients at the boundaries of life and rationality are especially vulnerable in attempting to retain or achieve autonomy, and so nurses have a delicate and difficult task. There is a strong relationship between autonomy and independence but they are not the same, though they are often confused. Inevitably, nursing has a special response where there is physical dependence but, as has been pointed out, it is quite possible to be fully dependent physically and yet retain autonomy of thought and will. In such a situation the responsibility of the nurse is to accede to the wishes of the patient when possible and thus help the patient retain and exercise the dimensions of autonomy that are intact. Where autonomy of will is interfered with, then the nurse has a more delicate and complex task of reassuring and supporting the patient psychologically in decision-making.

There are practical things that nurses can do to respect autonomy such as actively to listen, to ask questions, to be imaginative, to supply information, to be supportive and to be patient. To be able to help patients come to the right decision for them, nurses must be thinking not only about their own views but about the patients' views. Part of how nurses can help is to enable the patient to talk through his inner convictions and the circumstances in which he finds himself, as well as the new option. Of course, nurses must always be sensitive to the possibility that such discussions may not be held with a nurse at all and indeed the nurses' role may well

be only to try and facilitate it. It is important that nurses try to make as much effort as possible to secure personalised care for the elderly and ill because the evidence from the study shows that the potential clients have a touching faith in and dependence on the health care system in general and nurses in particular.

RECOMMENDATIONS

Analysis of the data and contemplation of the conclusions leads to the making of recommendations under three headings: education; management; and further study.

Recommendations for Education

- There is a need to secure an increased amount of time for the teaching of ethics in the nursing curricula. Such an opportunity would provide nurses with the skills in making use of significant ethical concepts. Nurses would also be able to have time to develop and confirm their ideas about the moral justification for acting in the way that they do or holding the views which they do. Such abilities would provide them with the security to take part in interprofessional dialogue and also help patients who come within their care.
- There is a need to further the use of nursing models in the education of nurses. Models which explain the practice of nursing will reveal new or better ways in which to understand and implement improved care.

- Though much has been said about communicating with patients and talking to them, there is still a need to further such convictions and skills among nurses.
- Since nurses still appear to have difficulties in being with patients and being able to interpret what information patients are trying either to gain or communicate, there appears to be a need to improve counselling skills.
- Though there has been much done to improve the care of the elderly in recent times, there is still a need to increase individualised care. This work suggests that the increased encouragement of autonomy in all its dimensions will help improve the well-being of patients and give an increased satisfaction to nurses as well.

Recommendations for Management

- Management at ward level should encourage nurses to be responsive to patient autonomy by allowing and encouraging nurses to spend time with patients.
- Nurses sometimes find it difficult to respond to patients' wishes because of limited resources. Management might find it possible to support the function of nursing which is to help patients do what they would do for themselves if they had the ability, strength or will.
- When patients need to make decisions of a major sort, then a nurse might well be the appropriate person to speak for the patient. Of course, this should only be done openly with the patient's knowledge and approval. Nurses might also need to

act as patient advocate when relatives are suggesting a different outcome from that which seems appropriate to the patient.

- Nurses need to be alert to the surroundings in which patients find themselves. Surroundings which lead patients to withdraw are liable to suffer interference with autonomy of will and nurses could be a vital force for improvement, and thus secure and encourage autonomy.

Recommendations for Further Study

- Since autonomy has been shown to be related to the process of reasoning, it would be of interest to examine autonomy and decision-making in children, particularly those who are suffering from long-term difficulties. A qualitative study would lend itself to the exploration of this area.
- Analysis of autonomy is needed in the care of the terminally ill where it could be expected that autonomy of will would be most seriously questioned by the patient's condition and prognosis. These data could be complemented by information about the perceptions of nurses and relatives. The group of patients could include matched pairs of elderly and younger patients.
- It would be helpful to describe the relationship of autonomy to depression since rationality of this group of patients is often questioned; and to compare the perceptions of patients and nurses in an attempt to understand and improve the outcome of care.

- An analysis could be made of the differences in autonomy as experienced by groups of people from different cultural backgrounds. Since health care is offered to an increasingly complex mixture of patients, it is important that the ideas and beliefs of nurses from a particular culture do not impose on those for whom they care.

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APPENDIX 1

Letter to Respondents



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Correspondence to:
 Mrs. Maureen S. Macmillan
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I am a nurse who is working at the moment in the University in a Research Unit that, after gaining information, seeks to make recommendations that will improve the care of people in the National Health Service. For some time now I've been interested in older people, their health and what it is like for them to be in and out of hospital. So that I can really find out what such people really think about their lives, including the care they get, I'd like to talk to some of them. Since it is difficult to have conversation in hospital I thought it would be better if I could talk to various people at home.

Recently I spoke to your minister and told him about my work. I asked if there were any members of his congregation who had been in hospital and back home - and if they would be prepared to speak to me. He mentioned a number of people, including yourself, whom he had spoken to and seemed willing to speak to me.

I would like very much indeed to come and meet you. If you'd prefer I didn't come then do feel free to contact me; the address and telephone number are at the top of this letter. If it would be convenient I'd like to come and see you on

at whatever time would suit you, or another day if this isn't convenient. Of course, if you change your mind and would rather not speak to me you can tell me at the time.

I'm looking forward very much to meeting you.