FACTORS THAT ARE IMPORTANT TO THE QUALITY OF LIFE OF DYING PATIENTS

A study of the quality of life perceptions of terminally ill people in a hospice and the acute wards of a general hospital.

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ABSTRACT

Quality of life research requires closer definition of dimensions of quality of life for different groups of patients - a stated aim of terminal care is quality of life for the patient. This study has three aims, (1) To identify quality of life factors chosen by terminally ill people. (2) To explore the context of priorities and expectations in which these factors were given. (3) To apply the findings to the clinical situation. The main research instrument has been the interview centred on the question - What is important to your quality of life today? Visual analogue scales, participant observation, records and staff-questionnaire have been used for triangulation purposes. The research is based on three samples, (1) A 'random' sample of 52 hospice patients - 74 interviews. (2) A convenience sample of 22 hospice patients - 22 interviews. (3) A convenience sample of 22 patients from the acute wards of a general hospital - 23 interviews.

Spontaneous responses indicate that quality of life comprises a spread of concepts consistent with living life as fully and as much in control as possible. The findings indicate, (1) A new definition for quality of life appropriate to care. (2) A missing dimension of 'comfort' factors in quality of life instruments. (3) The relevance of organisational aims to the provisions in care (4) Gender differences in approach to terminal illness. (5) 'Supported-living' is more appropriate to dying than the traditional 'sick-role' concept. (6) Physical and emotional comfort needs have priority. (7) Reference to past institutional experience highlights some disturbing incidents. (8) 'Expertise', 'interaction' and 'organisation' are all important to quality of life in care.
ACKNOWLEDGEMENTS

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I remember with great gratitude the respondents who so willingly gave of their best; so much inspiration has come from them.
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INTRODUCTION

The ultimate consequence of life is death,
the ultimate consequence of quality of life,
is quality of dying. (Van Hall. 84:24)

The research question, What factors are important to the quality of life of dying patients? arose from a clinical situation. Some years ago a visit was made to an elderly woman in her home - Mrs Jones is not her real name. Objectively her quality of life might well have been assessed as very poor - she was immobile and suffered double incontinence. Since her incontinence was not well managed she was too embarrassed to meet friends or attend the village meetings that had meant so much to her. The relatives with whom she lived were out at work all day and she was lonely. She was facing the end of her days. Yet she expressed some sense of delight with life as she had managed to save enough money for a 'respectable' funeral. This meeting of a need for social esteem, symbolised by the 'respectable funeral' was a positive factor in her assessment of her quality of life. She was able to use this as an emotional defence in her situation.

This provided me with an introduction to the complexity and subjective nature of the quality of life concept. There was a sense of wonder in the presence of human flexibility and adaptation, and the idea occurred that it would be helpful to understand more of the factors that were important
to the quality of life of patients like Mrs Jones, for the aim in terminal care, when cure is not possible, is to enhance the quality of life that remains (DHSS, 1972; McGinnis, 1986).

Some years later the same phenomenon was observed amongst patients in a hospice; many appeared to have a greater sense of well-being than might be objectively associated with their situation, of being in an advanced state of cancer. They appeared to be finding factors that boosted their satisfaction with life. The desire to explore these factors resurfaced, and this time it was possible to undertake a research project, which is the subject of this thesis.

This is a study of quality of life factors which were important to two samples of patients in St Joseph's Hospice, 65 in all, and a further sample of 22 similar patients being cared for in the acute wards of a large general hospital. (Appendix 1)

THE AIMS OF RESEARCH AND THEIR BACKGROUND

The broad aim of the research was to identify factors subjectively chosen as important to the quality of life of terminally ill patients receiving institutional care, seeking to understand the context in which these factors were chosen; then to present the findings in a way that could be helpful to the clinical situation. This aim is broken down into three subsidiary aims:
AIM 1. Identification of quality of life factors chosen by terminally ill patients

A review of literature indicates that much knowledge has been gained in the clinical situation, and in research, of the needs and concerns of dying patients. (e.g. Twycross, 1975b; Kubler-Ross, 1970; Saunders, 1984; Hinton, 1963). However there is less known about the needs and concerns that are subjectively identified by terminally ill patients as specifically contributing to their quality of life, and the literature indicates that they may have different priorities from those who are well (Enquist, 1979; Krant, 1974; Watson, 1984).

In recent years quality of life measuring instruments have been developed, and used with chronically sick and dying patients, particularly to compare one form of treatment or type of care with another. Many of these instruments have been devised with heterogeneous samples, groups of patients with different diseases, with or without the addition of 'normal' healthy persons (e.g. Spitzer, 1981; Padilla, 1983), or with patients in various stages of the same disease (e.g. Holmes and Dickerson, 1987; Young and Longman, 1983). As such, they do not necessarily reflect the concerns of dying people who frequently change their values with the known approach of death (Staps, 1983).

The first aim of this project is therefore to isolate broad types of quality of life component, and then identify how they are perceived by patients in terms of their symbolic meanings. For example social esteem was very important to the quality of life of Mrs Jones, and in her situation this took the form of feeling assured that she would have a
'respectable' funeral. The focus therefore is on the world of symbols that provide meanings in living (Jaeger and Selznick, 1964). The research is assisted in this aim through insights derived from the sociological theory of symbolic interactionism (Mead, 1934).

AIM 2. Understanding the quality of life context In order to understand the factors that matter it is important to understand why they matter - the reasons behind the choice. When people are considering their needs, or what matters to them, their consideration is usually set within a framework of expectations, values, reference groups, and priorities (Merton and Kitt, 1950; Runciman, 1966; Maslow, 1970). These are the influencing factors or variables that guide assessment of need, and therefore the satisfaction of need, and of priorities within need which make for quality of life. The second aim of this project is to explore the context of expectations and priorities within which quality of life factors are chosen.

AIM 3. Presentation of the findings to help the clinical situation Although this research was of much academic interest for the researcher, much of the motivation for the study stemmed from the possibility that the findings might contribute to the care of dying people. As discussed in Section I there is evidence to suggest that all is not well with terminal care. In an early study Hinton (1963), concluded that hospital care left much to be desired. After researching into the care of the dying in the community Wilkes (1964) stated that this subject merited further study. Despite the considerable impact of the hospice movement together with other specialist units in the intervening years, there is
still much that needs changing. Nursing Mirror (1979:14) commented ‘No nurse trained or in training can be completely satisfied with the terminal care most patients receive in hospital’. Poor standards of care have continued to be identified in this field, both in the institution and in home (Mills, 1983; Wilkes, 1984; Tweedley, 1985; James, 1986; Field, 1989).

The aim to analyse and present the findings in such a way that they have the potential to help those who work in the clinical situation, is pursued using several means. First patients' quality of life factors, and their symbolic meanings are presented as raw data in the context within which they were received, thus bringing the feelings of patients to the reader in the way in which they were expressed. It is hoped that this will help to enhance empathy with the patients' perspective; for it is often stated that the patient is the best teacher.

Second, the data, and its context, is analysed in terms of the patients' perceptions of the sources of poor or good quality of life. These are discussed and a series of aims for care are suggested to assist the goal of enabling the patient to maximise quality of life. To this end throughout the analysis the quality of life response is related to three concepts developed in Section I. These are:
The organisation of care The organisation of care or the structure of care includes systems of care, staffing levels and expertise available, facilities, and education and the support of staff by other professionals.
The expertise of care The expertise of care relates to staff utilising skills appropriate to these dying patients.
The interactions of care 'The interactions of care' is a more modern term given to 'the spirit of care' developed in the historical discussion (Section I). It centres around qualities of interaction between staff and patient such as warmth and respect for the patient, empathy and sharing.

Lastly, consideration has been given to the form of language used in this thesis. In that an effort has been made to restrict the use of academic jargon it is hoped that it will be acceptable to the busy reader who does not have time to wrestle with the language of a variety of disciplines; for it is stated that the unnecessary use of such language prevents research from being utilised in the clinical field (Chapman, 1989).

Quality of life in this study is defined as the degree of satisfaction, or sense of well-being with life, felt by the individual (Andrews and Withey, 1976; Dalkey, 1972). This is a subjective definition that is appropriate to this study for the emphasis is on the perceptions of the respondents. In this instance, the focus is upon the components of satisfaction with life, rather than on its measure.

In this study those defined as terminally ill have been those people considered by professionals to have reached a stage of disease that is beyond cure, and that requires palliative care, and in whom the event of death is thought to be in the foreseeable future (Calman, 1984). However, as discussed in chapter 5 this definition has many practical difficulties.
HOSPICE AND HOSPITAL - TWO RESEARCH VENUES

The hospice appeared to be an ideal institution in which to undertake this enquiry, since my close contact with the wards over a long period, had shown that many patients were alert and appeared to be experiencing factors that boosted their quality of life: therefore they were likely to be able to answer a question as to what was important to their quality of life. Moreover there was ease of access as I was already employed there. However, as the research proceeded questions arose as to how much the hospice situation, expectations of the hospice, and specialist facilities were influencing the data. If they were to a major degree, then over and above the usual limits on generalisation of research, the findings could be considered completely irrelevant to staff working in other types of institution who care for the majority of dying patients (Office of Population Censuses and Statistics, 1986). For example, the findings relating to love and belonging were interesting. Was the enormous emphasis that the patients gave to this related to the fact that 18% of the hospice patients had no family and friends? It was important to know whether other patients would talk so spontaneously of the need to find belonging in the institution.

For these reasons it was considered that it would be highly beneficial to obtain a further sample of similar patients from a general hospital. Many quality of life factors identified by the hospice patients related to the meeting of basic needs and the solving of problems associated with the effects of disease, which were likely to be shared by hospital patients.
It was important to discover how quality of life factors were identified in the different situation of the busy acute ward. It became possible to undertake this further stage of research in a large general hospital after leaving the hospice in December 1986.

SAMPLES

1. The Hospice 'Random Sample'
Seventy-four interviews were conducted with a random sample of 52 terminally ill cancer patients between 1984 and 1986. The repeat interviews with 23 patients, always at the patient's request, enabled some observation to be made of change over time. (The respondents in this sample have been identified by alphabetical lettering, e.g. Mrs A).

2. The Hospice Convenience Sample
Over the same period as the 'random' sample 14 interviews were conducted with 13 patients similar to those in the random sample. As the ward staff became acquainted with the research they made suggestions as to likely respondents. This was partly to help the researcher but was often accompanied by such comments as, 'It will be good for him to talk - he likes to talk, is lonely, or is very withdrawn and it might help'. These patients form this separate sample, and they have added much illumination to the data. These respondents were asked the same quality of life question as the main sample and have been identified by alphabetical lettering followed by the letter 'D' (e.g. Mrs AD).
Hospital Convenience Sample

Twenty-three interviews were undertaken with a convenience sample of 22 patients in the autumn of 1987. Sixteen of these patients were suffering from advancing cancer, and were thought to be terminally ill, and 7 were suffering from other incurable diseases. All were being cared for in the acute wards of a hospital on the South coast of England. (The respondents in this sample have been identified by alphabetical lettering preceded by the letter 'P', (e.g. Mrs PA)

METHOD

As discussed in Section III a variety of research instruments were used:

1. The focused interview. This was the main method, designed to elicit response to the question, What is important to your quality of life today? At the end of the interview a quality of life visual analogue scale was presented to hospice patients if it was felt that they were not too tired by this time, and where it seemed appropriate in a sensitive situation. (Appendix 2)

2. Structured interview with staff. This was very brief, centring around what the staff member understood of the factors that were important to the respondent as an individual. (Appendix 3)

3. Participant Observation in the hospice only.

4. Use of patient records in the hospice only.
The last three methods were used for purposes of triangulation, or taking as many views of the situation as possible (Denzin, 1970).

**ADDITIONAL RESEARCH**

At the same time as this project was under-way some additional research was undertaken in the hope that it might provide some background illumination to issues that were arising in the research, and to the interests and circumstances of those having contact with dying people in a professional or family capacity. Reference has been made to this where it is appropriate. There were three projects:

1. **Nurses Interests in Terminal Care and Expressed Needs for Further Education in the Speciality.** A questionnaire was presented on a regular basis to groups of nurses attending the hospice for an educational session. 344 completed the questionnaire two-thirds of whom were nurses in general training. They came from 17 different centres of learning. (Appendix 4)

2. **Medical students opinions on the differences between the hospice and the general hospital.** Interviews were undertaken with a convenience sample of 7 medical students electing for a period of experience at the hospice. Three of these came from other European countries. (Appendix 5)

3. **Communication study** Since interaction between patient and professional was becoming an important issue in the study, it was decided to take an extra small convenience sample of seven terminally ill patients in the hospice in order to seek patients perceptions as to whom they would chose
to communicate with in certain circumstances, and the qualities in nurses and doctors that encouraged or hindered communication. (Appendix 6)

THE OVERALL PLAN OF THE THESIS

The thesis is divided into eight sections followed by a conclusion:

**Section I** Section I provides a background to the research and consists of three chapters. Chapter 1 looks at the treatment of dying people in a medieval monastic era when hospice care was offered, and then at the early scientific era from the 17th Century, with the rise of modern hospital systems. The different aspirations in care, and attitudes to the chronically sick and dying are discussed, with the implications for the quality of care that was provided.

Chapter 2 explores the development of the modern hospice movement. Chapter 3 explores issues relevant to the current drive to spread hospice principles to hospital and community care of the dying. Overall this section discusses the concepts of organisation of care, expertise in care, and spirit of care or interaction in care.

**Section II** Section II - chapter 4, explores the concept 'quality of life' in relation to its use in research and its relevance to needs theory and to the dying patient. It identifies a need for more research into subjective assessment of quality of life in the terminally ill.
Section III - chapter 5, discusses methodological issues basic to this project, giving some emphasis to those that relate to the ethics of researching with dying persons. This is followed by a general introduction to the findings.

Sections IV - VIII Sections IV to VIII - chapters 6 to 17 are focused on the findings; the same format is common to all sections. The first half of each section explores a broad quality of life factor or concept, that was important to dying people, relating it to the quality of life of respondents. The second half of each section explores the quality of life factor in the context of the provision of care with reference to its sources in care. It suggests aims for care. Throughout each section variations in response are analysed particularly as they relate to expectations, reference groups, age, gender and research venue. Each section ends with a conclusion focused on the three aims of the research.

The categories of quality of life factor featured in the sections are:

Section IV - Physical Comfort. - chapters 6 and 7.
Section V - Emotional Comfort - chapters 8, 9 and 10 and 11.
Section VI - Warm Supportive Relationships - chapters 12 and 13.
Section VII - Acceptable Identity - chapters 14 and 15.
Section VIII - Meaning in and for Life - chapters 16 and 17.

Chapter 18 the conclusion draws together threads from all the sections, reflects on the research and makes recommendations.
SECTION I

THE EXCELLENCE OF THE DAY - FRAMEWORKS FOR THE CARE OF THE SICK.
'Attitudes to suffering are largely determined by custom, religious teaching, and the presence or absence of moral principles upon which society is based'. (Baly, 1973:5)

A study of the history of the care of the sick and dying points to the relevance of the social beliefs and attitudes of the day to the quality and type of care that was provided. Different eras provide differing frameworks for care, each era having its own form of excellence as well as of neglect. However, the influences of religion, custom and belief do not end abruptly but weave throughout the centuries. The social historian Trevelyan (1942) therefore asks the question, into what periods shall social history be divided up, and concludes that nothing is clear cut, there is no single moment when all Englishmen adopted new ways of life or behaviour.

This situation is particularly exemplified in the history of the care of the sick and dying; the influence of early modes of care have waxed and waned over the years emerging strongly this century to have a major impact on the care of the dying. Today with an increasing elderly population, and therefore more chronic degenerative disease; and in a climate of continual change within the Health Services, there is a striving to bring the 'excellences' of our time to the care of the sick and dying. This is a process of redefining the frameworks of care in seeking to combine the best traditions of the past with new scientific insights, in order to help each patient to attain the maximum quality of life that is possible;
effort spearheaded by the hospice movement, with its roots in early history.

This section takes a historical and sociological perspective as it looks at the issues relating to three frameworks of care for the dying - first, its organisation in terms of a place and a workforce - 'the organisation of care'; second, the basis for work with the individual patient - 'a conceptual basis for the work of care' which underlies the aims of care, and third, the spirit within which that care is conducted - 'a spirit of care'.

The time frameworks within which these concepts have been explored are:
1. The early monastic era from the 6th century - chapter 1.
2. The era of rising science from the 17th century - chapter 1.
3. The modern era from the beginning of the 20th century - chapters 2 & 3.

This exploration of the history of terminal care provides a background and explanation for the situation today. The emphasis on the relevance of the organisation of care, aims of care and spirit or interaction of care to the standard of care offered provides a conceptual basis for the analysis of the patients' response in this study.

THE ERA OF MONASTIC CARE OF THE SICK
When in the mid-19th Century Mother Mary Aikenhead, the founder of the religious order of The Irish Sisters of Charity, wished to provide a nursing home for the sick poor, she turned to a medieval model of care for its name and called it a hospice. after the medieval hospices that
provided hospitality and care for the traveller and the sick (Lamerton, 1980). 'Hospice' is defined (Chambers, 1973) as 'a house of entertainment for strangers especially one kept by monks, a home of refuge' and linked with 'hospitable' - 'kind to strangers, welcoming and generous towards guests', and is thus placed within an organisation of work, a basis and a spirit of work. Thus Mary Aikenhead brought the term 'hospice' once more into the language of the day, and through others who were to follow her, strongly influenced the founding of the modern hospice movement. Perhaps it was not surprising that someone who had founded a religious community to serve others should turn to a monastic model of the past for she shared many of its beliefs, but the connection would not have been made with the old hospices had they not represented the 'excellence' of their day, and still held something that could contribute to the present.

In medieval times medicine, nursing and welfare were largely in the hands of the monasteries. The orders of St Benedict, from the 6th century, and St Augustine, from the 11th Century, particularly undertook this work amongst their other duties, and for the military field, from the 12th Century, the Knights Hospitallers of St John and the Knights Templar (Baly, 1973). An order specifically set up to minister to the sick and dying was founded by St Camillus de Lellis 1550 - 1614 (O’Connor, 1987). The religious beliefs of the time, held by the 'religious' within monastic communities, and held at least on the surface by the general population, provided firm social frameworks for the organisation of care, for interaction with the patient, and for a guiding spirit of care.
A Framework for Organisation of Care

To the entrant to the religious order the monastic life was seen as a means of journeying towards God and salvation, this way of community being God’s chosen way, and the only way for him (Baly, 1973; North, 1987; De Waal, 1984). The monastery became therefore for its members a school of the Lord’s service, the medium through which they learnt more of the mandates of Christianity and put them into practice. In seeking to follow Christ and fulfil the Christian imperative to relieve suffering, as the Good Samaritan, the monasteries provided a ready made community, an ideal organisation in which the care of the sick and dying could take place.

But, the monastic ‘rule’ outlined not only general applications of faith but its detailed workings in daily life, thus providing firm organisational guide-lines that were important to the well-being of the carers and of the sick. In the introduction to ‘Organization Theory’ Pugh (1971) states:

‘the task of management can be considered as the organisation of individuals’ behaviour in relation to the physical means and resources to achieve the desired goal’. (P. 11)

Monastic rule sought to achieve its goal by management of men and materials in the organisation of the lives and behaviour of members of the order, and in conserving its resources. The means by which the Benedictines, for example, did this, (their Rule being widely accepted in Europe from the 6th Century) was through a system of regulation whose characteristics still have a relevance today. There were plans for a
clear but benevolent leadership topping a flattened hierarchy, which provided a role model; a stable work force with defined and shared roles in which the idea of balance reigned throughout, for neither the monastery as a whole nor its individual members were expected to work until they reached 'burn-out'. This was to be teamwork in which there was respect for the other and patience with weakness. Both material and human resources were to be carefully conserved and recognition given to the individual needs and potential of members of the community (De Waal, 1984). The characteristics of organisation were therefore good leadership, teamwork, clear goals, appreciation and conservation of scarce resource, and organisation, that was appropriate to the needs of the institution as well as those of the society that it served.

A Framework of Understanding for Work with the Patient

The shared religious beliefs of the time, within monastery and between monastery and the rest of society, provided not only a framework for action, but one for interaction in that they provided a basis for communicating relatively easily with the dying. Life was viewed as transitory, to be followed by an immediate after life, or in the earlier years a period of rest and then an awakening to life eternal. Beliefs also provided some answer to suffering and evil in that it was viewed as coming from outside of man. It had to be endured in this life but would be overcome in the next (Aries, 1981). Thus there was some comfort for the worst aspects of sorrow and death; to some degree death had been 'tamed' (Aries, 1981). and a basis for interaction with the dying provided, for when there is a socially recognised, accepted, and acceptable answer to major life events, then there is a foundation for discussion of such
events, and for a relationship with those who symbolise them, tragic though they be.

Thus, patients were washed and fed, eased with traditional Greek and herbal remedies, exhorted to bear the Will of God, and, helped to prepare spiritually for the life to come (Baly, 1973). This view of the patient enabled carers, according to the abilities of the day, to meet a range of needs including the physical and the spiritual, for their awareness of need went beyond the purely physical, and their acceptance of death enabled them to come close enough to dying persons to treat them as, what would be known today, as whole persons.

A Framework for a Spirit of Care.

The monastic 'rule' stipulated that the sick, as indeed all needy people, were to be cared for in a spirit of reverence; first, the stranger was to be received 'as Christ', 'Let everyone be received as Christ' (De Waal, 1984: 5), and second, as followers of Christ the monastic community were to learn to grow in humility or lowliness of mind, esteeming others. In Benedictine Rule this humility was also to be a corrective to prevailing social attitudes, to be especially exercised towards the poor, restoring to them a dignity, 'most particularly because the natural tendency was to revere the rich' (De Waal, 1969:5). Third, as the 'religious' had entered the monastery as a way of subjecting the self to seek the Will of God through others, those others were in a symbiotic relationship, or partnership with them in reaching the chosen goal, and as such to be nurtured. Lastly, if life was a journey, then all were on that journey and the dying were ahead on the ascent. The dying were therefore considered in
certain very important matters, to have greater knowledge than those
caring for them and viewed and reverenced as 'prophetic souls' (Robinson,
1981; Stoddard, 1979). There were thus many reasons for treating the dying
with great respect, their words would have borne some real weight.

Respect, reverence and courtesy however, were not enough. The 'Rule'
demanded that people be received with genuine warmth. The ideals were
‘fervent love, pure love and humble love’ and the community were
instructed: 'Never give a hollow greeting of peace or turn away when
someone needs your love' (De Waal, 1984:5). The characteristics of the
humble love that was to be given were very practical in providing a
stability of care that did not give up, or run away, in the face of
difficulty or unpleasantness:

' For the love of Christ - Christ in people: in the brothers, in
guests, in the invalid however tiresome, in strangers and
travellers' (De Waal, 1984:5)

These characteristics of a spirit of care bear a strong resemblance to
the Pauline description of unpatronising love as - 'suffereth long and is
kind ... is not puffed up' (1, Corinthians ch 13). Thus there was a basis
for offering, and continuing to offer, a place of care for all, including
those with socially repellant properties, with horrifying disease, the
angry, the difficult and demanding. Everyone was to receive continuity of
welcome and support. The characteristics of the spirit of care were
respect for individuals, who were to receive warm service based upon a
practical form of love that enabled the carer to provide consistently for their needs.

The unity of belief of the day provided therefore most powerful frameworks for a model of care for the sick and dying, at least in the early monastic days, for it has been suggested that within a century or so at least one hospital was becoming more selective of its patients (Dunlop and Hockley, 1990). This framework included - the organisation of a cohesive, stable team of people highly motivated, to the best of their ability, to meet physical and spiritual needs, and as important for the quality of life of the patient, relationships in which he was loved, honoured and valued as a continuing part of the wider social community. However, the basis for this 'excellence of the day' was also one of neglect in other areas for since suffering was to be accepted, and dissection of bodies forbidden there was little sanctioned impetus to seek for the causes of suffering and disease and try to find a cure. This had to wait for a scientific era.

THE ERA OF RISING SCIENCE AND SECULARISM - the 17TH - 19th CENTURY.

With the dissolution of the monasteries in the 16th Century most of their work of caring for the sick disappeared, the hospitals associated with monasteries suffered disendowment and only three were left, of which St Bartholomews in London is one. In the subsequent years there was little concern with 'excellence' in the care of the sick. By the seventeenth century a mixture of new customs, beliefs, and knowledge were combining to provide frameworks of care that had different characteristics from those of the monastic era.
A Framework for the Organisation of Care.

Whilst these centuries were marked by a general decline of religious belief, particularly amongst educated males; they were also characterised by strong surges of humanitarianism, a particular mark of the 18th century (Trevelyan, 1942). Humanitarianism was often associated with Protestant revival, exemplified by that stemming from the rise of Methodism (Hobsbawm, 1962). The outcome was an emphasis on philanthropy of all kinds. Many new hospitals were founded for all sick people, particularly the sick poor, and were established in principal towns. Between 1725 and 1745 in London, five of our now famous teaching hospitals were set up. Between 1770 and the end of the nineteenth century 154 new hospitals had been established in Britain (Trevelyan, 1942).

These were the Charitable Hospitals, but in contrast to the monastic age in which care came from a collective approach, the source of this advance was the initiative of individuals who proposed an idea and went on to organise and co-ordinate voluntary effort around it. This reflected an individualistic spirit of the age. Not until nearing the end of the nineteenth century was the individual approach followed by community action through municipal and legislative action. As far as philanthropy was concerned, this was an age of charismatic leadership.

Another major strand of influence was the rise of science, and with it of medical knowledge that enabled religious and humanitarian philanthropy to effect the changes that were needed, for the ambition to provide hospitals would have been unlikely to have arisen if it had not been seen that such institutions could make a very positive contribution to the care of
patients. This they had previously been unable to do for they had offered little in terms of good medical or nursing care, but much in terms of the risk of infection (Baly, 1973). This possibility sprang from the advent of new knowledge.

The eighteenth century saw medicine beginning to emerge from traditional superstition to a new scientific approach based upon research into the physical. The barber surgeon was becoming the specialist in surgery, and the science of the physician and apothecary were developing apace; the practice of midwifery was being revolutionised. These changes resulted in altered relationships between professional and patient. When the physician had comparatively less to offer he had been heavily dependent upon the patronage of the rich and powerful, who thereby had power over the consultative relationship. With new and much sought after knowledge this balance of power was beginning to swing towards the doctor (Morgan, 1985; Jewson, 1974); for the various approaches to the cause of disease, including the personalistic and naturalistic, were becoming reduced to the idea that cause lay with the body; and the physician was 'the master' of the body (Jewson, 1975).

Thus a new framework for the organisation of cure and care was in formation, and its power structures differed greatly from those of the old eras when the carer was there to bow to the needs of the general sick as in the monastic days, or more latterly the rich sick. This change in the balance of power between doctor and patient has continued into the twentieth century. Unfortunately for the welfare of the chronically sick and dying, and those with common diseases, this power extended to the
selection of patients to be treated and admitted to the new hospitals. The emphasis on the scientific, the interesting and unusual eventually left for them little place in the Charitable hospitals. By the end of the nineteenth century these institutions together with more newly founded specialist hospitals were selecting patients who would best serve the development of medical science and education, and rejecting the rest; the action and organisation, in major hospitals, was heavily orientated to the esoteric and to cure (Baly, 1973). An additional system of care was eventually to emerge with the Poor Law Board provision in 1871 of hospitals for the poor and chronically sick, but these did not command the same status and resources as the major teaching hospitals.

However, there were some few institutions in Europe based on earlier models of care that greatly influenced change for the better. Among these was one of a Roman Catholic Order founded in 1815 by Mother Mary Aikenhead. The Irish Sisters of Charity began to work amongst the orphans, the sick, and poor in Dublin. A few years later this was to lead to the opening of a nursing home for the care of those very sick and dying patients who could not be nursed at home, it was to provide quieter more homely care than was possible in a hospital. Mother Mary Aikenhead called it a hospice since she considered death to be part of a journey rather than an end of life, they were thus caring for travellers (Lamerton, 1980).

Another characteristic of earlier monastic care that was generally lacking in the hospitals of this era was efficient teamwork in the form of a ready band of skilled and highly motivated carers. The nurses of the time were
ill informed and ill paid, with a status akin to domestic servants. This situation began to be transformed as Florence Nightingale brought 19th Century Protestant, individualistic and self-actualisation motivations to reforming nursing care, adding to these strong leadership and mathematical science. This marriage of emerging ideas lead to the inauguration of a professional nursing service that could be teamed with medical advance, but this was not until nearing the end of this era. However, these centuries mainly lacked those characteristics of organisation that had proved so useful to the care of the sick in early monastic times - a model of organisation appropriate to a range of sickness, including that which was terminal, and a skilled team of carers with clearly defined and shared roles.

A Framework for Work with the Patient.

From the 17th century onwards inter-related strands of change in religious belief, custom, and scientific knowledge all had a reducing impact upon the basis of interaction with the patient as a ‘whole person’, in that they tended to reduce communication to the purely physical, and this might be reduced still further if the patient was dying.

For many people the old comforting certainties of life after death and an evil external to man, had been removed by decline of religious belief and understanding, and even for the religious faithful the new emphasis in teaching was on morality rather than dogma. There was thus less support to be had in the facing of life’s tragedies than when there had been unified beliefs that strongly addressed human vulnerability. For these reasons Aries (1981) sees this as an age when death had to be denied, and kept
remote, particularly because it was all around and imminent. Later for a
time, in the Victorian age, death was romanticised as a subtle form of
denial but this form of fantasy was soon to break down in the face of
unpleasant reality. Death was therefore no longer 'tamed' (Aries, 1981)
and if thoughts of death were best avoided then one way of achieving this
was to avoid the dying, and especially avoid discussing death with the
fatally ill patient. This immediately eroded ready communication with
such patients, as well as interaction on the basis of total needs, for if
the situation could not be acknowledged then the relevant needs could not
be approached.

Science played its part in reducing the interaction base with the patient
as a whole person in the intense focus upon the physical. This distracted
from psycho-social issues reducing the patient to the anatomical and
physiological. Moreover, if the doctor was foremost a scientist, and the
patient the object of his study, then scientific objectivity required a
distancing from the patient and his emotional problems - which Armstrong
(1983) defines as a part of the 'panoptician gaze', the characteristics of
which were objective observation of behaviour with no contact between the
observer and the observed. This approach was also a tool of power in that
the observer responded to and manipulated the variables in the situation.

Another reason for a growing gap between physician and patient was that
the former represented a new 'wise' in society - the increasing knowledge
of professionals drew them apart from those who had had no such education
and therefore could not be expected to understand. A new language was
arising of which only one side could partake. Thus compared with earlier
times, there was a general drawing away from patients as ‘whole persons’. Taken together these influences of the scientific age produced a framework of very different interactions with the patient summed up by Florence Nightingale in 1859:

'It is quite surprising how many men practically behave as if the scientific end were the only one in view, or as if the sick body were but a reservoir for stowing medicines into, and the surgical disease only a curious case the sufferer has made for the attendant’s special information'. (in Lamerton, 1980:17)

Lastly, as far as the dying patient was concerned, since the emphasis of scientific advance was now strongly on cure, death represented failure, providing another motivation for the desire to limit association with his situation. Thus, the loss of comforting belief, and the scientific drive towards cure had meant that the dying represented two very unacceptable symbols, that of death, something everyone feared, and that of scientific failure. This was a doubly negative symbolism, very different from that of the revered and useful ‘prophetic soul’ (Robinson, 1981) of the earlier years. Quite apart from the limits imposed by the focus on the diseased part, and on distancing objectivity these were enough to severely limit the interaction between the dying patient as a whole person, and those who cared for him. The bases for easy communication with the dying had largely gone.
A Framework for a Spirit of Care

These centuries were marked, at times, and in places, by the same loving spirit of service that had been a feature of monastic care. One of the aspects of the care of the Kaiserworth Deaconesses that had particularly impressed the pioneering Florence Nightingale, in advance of her day, was the degree of 'pure devotion' (Baly, 1973) that marked their response to patients. This was the love that had also been present in the earlier founding of the charitable hospitals, resulting in, 'devoted attention to the poor' (Trevelyan, 1942: 344). having at its roots a spirit of service to the individual as valuable in his own right.

However new advance not only brings new opportunity, but a greater complexity of situation in which interests may conflict. In the intense drive to understand and conquer disease such conflicts could lie between the service to the known individual and to the wider cause of discovery for unknown others. Thus in the cause of research and progress, some from whom it was no longer possible to learn could be denied care. Motivation was further complicated by the potential for self-advance for the professional in extending the frontiers of medical knowledge; it was recognised at the time that some of the specialist hospitals were founded in a spirit of gross self-seeking (Baly, 1973). Here there was change, and sometimes reversal of relationship between the professional as server and the patient as the served. Whatever the motivation or the mixture of motives, they involved a change of attitude, or spirit, towards the sick; there was a different symbiotic relationship between patients and those who cared for them but it did not always work out to the advantage of patients. In the face of the growing power of the professional the
esteemed sick of the past - 'Our Lords the Sick' (Stoddard, 1979) were now more likely to be recognised as the humble patients who were expected to be deferential and effusively grateful (Goldie, 1982).

Thus these years saw a change from a relatively simple society governed by a universal religion to one that was much more complex in its beliefs, knowledge, and customs. Correspondingly the situation in health care was more complicated, there was more room for tensions between cure and care, and a change in balance of power between patient and professional. The frameworks for the organisation of care, for work with the patient, and for the spirit of care had changed in varied and subtle ways, to the benefit of the cure of some of the acutely ill, rather than of all. The particular 'excellence of the day', was in this growing ability to cure which was focussed on some patients; but the chronic sick and dying did not share equally in scarce resources. One gap was being filled whilst another was being created, to await for another century in which all the inherited strands could combine to begin to seek for a remedy.
Around the turn of this century local efforts were being made on both sides of the Atlantic to fill some of the gaps in the care of the dying and chronically sick; this was achieved through the founding of several institutions the source of which was philanthropy. In Britain in 1891 an appeal was made for public funding to set up a home for the mortally ill in London - the need for this must have been widely recognised for the funds were provided and the Hostel of God was founded in Clapham. Around this time Methodists founded St Luke's house for the dying poor, also in London. In 1899 the Calvary Hospital in New York was instituted by Catholic lay women. In 1900 a group of Irish Sisters of Charity came over to London to work amongst the needy in the East End, this venture resulted in the founding of St Joseph's Hospice in 1905 in order to provide adequate care for those dying, mainly of tuberculosis. Their ability to be able to do this sprang from the recognition of the necessity of their work by benefactors, amongst them a Jewish philanthropist. Later, in 1909 there was another innovation when nineteen beds were set aside for the care of the dying within a hospital devoted to treating disease - The Royal Cancer Hospital, now the Royal Marsden.

Thus in some quarters there was a climate of opinion as to what might be required to be done to help the terminally ill. It is interesting to note that members of religious communities were the people who mainly undertook this work as appropriate to their motivation and organisation; for before long the Hostel of God was handed to Anglican nuns to run and Calvary
Hospital to Dominicans (Downie, 1974; Lamerton, 1980). Whether of religious order or not, the aims of these institutions were reminiscent of those of the earlier monastic hospices in the attention given to both physical and spiritual care. Dr Howard Barrett (1894), the founder of St Luke's House wrote of those they cared for:

'to whom, while life shall last, we can give peace and rest, and much ease from pain, the best food, the best medicine, gentle hands to tend them, friendly voices to cheer them, and the good tidings of the all-embracing Love and the Eternal Life'. (in Lamerton, 1980:18)

Whilst these comprehensive aims were not couched in terms of 'quality of life' or of 'living', used so much in the hospice movement of today, they were clearly their forerunner in conception. Thus, the idea to meet the needs of dying people did not spring at this time from a single movement but from a wide awareness of a gap in care, and from a variety of beliefs and philanthropic effort.

The awareness of the plight of dying patients and of their families was increased with the founding of the Marie Curie Foundation in the 1950s; their first survey of cancer patients being nursed at home (Marie Curie Memorial Foundation, 1952) identified much hardship, and recommended the provision of skilled nursing care and hospice type accommodation for those who could not remain at home. They considered that this would be more acceptable to patients than the often dreaded public ward of the hospital. In the meanwhile from the late 40s charismatic leadership was in the process of formation to begin to meet this need on an international scale
when Cicely Saunders, then an almoner at St Thomas' Hospital, inspired by Christian belief and empathy with a dying patient, began to prepare for this as her life's work. After undertaking medical training she joined the staff of St Joseph's Hospice to research the clinical needs of dying patients, and began to formulate her plans based upon the experience there and in other institutions. Her own hospice - St Christopher's, was opened in 1967 and a Home Care Service instituted in 1969 and Bereavement Service in 1971. The modern hospice movement, comprehensive in nature, was being founded.

The Modern Hospice Movement Begins

It is interesting to note how closely the frameworks for the work of care at St Christopher's were modelled on the old hospice ideal, Dr Saunders felt that the work that she intended to inaugurate was 'only possible in a home with some sort of religious foundation and one where staff have time ... and appreciation of the individual' (Saunders, 1963:25). She viewed the patient as a traveller:

'My bags are packed and I can leave with a tranquil heart at any moment' I think that this is how we pray for all the patients who will come to us' (Saunders, 1965:4).

St Christopher's was to be a religious foundation that was ecumenical and undenominational, a work to be 'truly to the greater glory of God' (Saunders, 1965:4) but it would draw on the help of people of a wide variety of religious beliefs and none, the criteria being the commitment to serve patients. (Saunders, 1981)
In its emphasis on living the hospice was also to be a response to the euthanasia movement, an affirmation that quality of life whilst dying did not have to be so bad that an ending should be sought:

'In the early 60s I came upon the literature of the Voluntary Euthanasia Society and realised how important it was not only that pain relief should be more widely spread but also that people should understand that life could be lived to the end' (Saunders, 1981:6).

The hospice staff, of all disciplines were to be a community or team that hopefully would grow together, and appreciate the contribution of each member, whatever that was:

'it must also be a place where everyone knows that the individual contributions matter and that there is no hierarchy of importance in what is done' (Saunders, 1965:2).

Stability towards the patient rather than to the institution was to be a characteristic of the care, through times of clinical perplexity, difficulty and discouragement carers were not to run away from the patient:

'Certainly they (the patients) are not all going to be saints. Some will be ... Others will be splendidly maddening ... 'Even when we feel we can do absolutely nothing, we will still have to be prepared to stay' (Saunders, 1965:2).
Humility was also to be a mark of relationship with patients, the kind of humility that showed willingness to learn from them. Thus patients were to become active rather than passive in care, if that is what they wanted:

'We want St Christopher's to be a place where all kinds of people can join us to learn from our experience and learn from our patients with us'. (Saunders, 1965:2)

Up until this point there had been little in such ideals to separate them from those of older models of care, but to these were added an emphasis on teaching and research, particularly in relation to relief of distress, and the inclusion of family with patient as the unit of care:

'We want to plan and carry out research in the relief of distress such has not been done anywhere else' ... 'Planning an ideal unit is not enough ... if teaching is not a vital part of what we do' (Saunders, 1965:2-3).

The breakthrough into the present had come in the combining of the best of modern scientific understanding with those of the best aspects of caring for people in the monastic era. A spirit of one age was meeting with that of another.

But, much of the spirit of traditional care had been lost with the surge of science and technology and so the frameworks for the work of care needed to be be firmly placed within an over-ruling spirit of care, that of warm service to the patient as a unique individual:
'In the first place it demands that all the work at St Christopher’s should stem from respect for the patient and very close attention to his distress ... they (the patients) needed warmth and friendship as well as good technical care' (Saunders, 1965:1).

The ideas that formed the basis of the founding of St Christophers were truly innovative for the day but it would have been very difficult for St Christophers to have been instituted and the modern hospice movement expanded and consolidated in the subsequent years, unless these ideas had been in accord with a growing body of public and professional opinion including that of patients, providing the necessary encouragement, support, and finance. Indeed many of the aims for the new hospice were in line with the results of academic research; and Dr Saunders quoted extensively from this literature in support of her views (Saunders, 1967).

Up until the 1960s the subject of thanatology had been little studied or written about but this situation changed in this decade until by 1979 there was so much literature on the subject that any one person had difficulty keeping up with it (Simpson, 1978). A selection of this literature is discussed here within a historical and developmental context, further selections feature in every section of this report.

The Background of Research
An early and influential book written in 1935 containing a series of lectures given at Harvard University by a family doctor, was concerned with the care of the dying, the aged and the dead; this was published in Britain in 1961 (Worcester, 1961). Around this time several surveys
indicated the need for improvements in care of the dying and support for their families (e.g. Aitken-Swan, 1959; Hughes, 1960; Hinton, 1963). In his study of the care of the aged in general wards Exton-Smith (1961) found that amongst other problems it was very difficult for patients to be understood and treated as individuals in the busy ward environment.

Sudnow, a sociologist, made an important contribution (1967) to the understanding of the ways that American society organised dying, how bad news was broken, and dead bodies handled. His work illuminated the behaviours of the staff concerned and showed that not all patients with life threatening illness received equal access to treatment, the old, the poor lagged behind in priority. Some years later the large and influential survey undertaken by Cartwright and others (1973) confirmed that in the care of the dying there was much deficiency. This retrospective study of the lives and care of a stratified random sample of 785 adults aged from 15 years, who had recently died, covered 12 areas of England and Wales and was based mainly upon the reports of relatives. Much inadequacy of care was revealed that had resulted in physical and mental distress to patient and family, and which was made worse by lack of co-ordination between services. Many recommendations for improvement were made including more emphasis in medical education on caring and relieving rather than curing, more research on symptom control, and more investment of financial resource (Cartwright, 1973). Surveys such as these emphasised the need for hospice type provision and ideals in care.
One focus of interest at this time was bereavement; Bowlby (1961) explored the processes of mourning; for the dying and their family this can take a form of anticipating loss, a mourning of the loss that will occur in the future (Aldrich, 1963). Gorer (1965) undertook a major study, using interviews with a sample of over 1500 respondents, of all classes in every region in Britain. He identified a widespread social isolation of bereaved people, and its source as that of lack of any socially recognised behaviour after the funeral. In 1964 Parkes used case records to study the effects of bereavement on the physical and mental health of widows, and in 1970 he undertook a longitudinal study of the reactions of London widows to the deaths of their husbands. Later in 1973 he summarised the effects of the stress of bereavement. These classic studies indicated the very real need for the family to be supported as part of the unit of care, and this became widely accepted as part of hospice philosophy.

These years saw the beginning of exploration of many other aspects of death and dying as clinicians, sociologists, psychologists and philosophers applied their own insights in a search for new conceptual frameworks and models. These were not only academically interesting but were useful in the clinical field. One important, and very large, area of study was that of the meaning of death and dying to individuals, well or ill, and to different social groups. Feifel, an early pioneer, focused on the real concerns of patients as well as bringing together a group of writers who approached the subject from a variety of points of view, that included the practical with the religious and philosophic (Feifel, 1959). Welshman (1972) in his psychiatric study of terminality introduced the
concept of 'appropriate death', which to be appropriate, should be compatible with the ego-ideal. He outlined the conditions that were implied - physical and mental suffering and disability kept to a minimum, opportunity to resolve conflicts and make own choices in the life that remained, including that of solitude or company, consciousness or unconsciousness. He concluded:

'An appropriate death in brief is a death that someone might chose for himself had he the choice'. (P. 41)

Other influential writers explored the philosophical aspects of death, which included the meanings of life and the significance of man (e.g. Becker, 1973; Frankl, 1963; Jung, 1959; Teilhard de Chardin, 1960; Tournier, 1957). Fulton (1965) equated a 'dignified death' with the significance of man. Some work, for example that of Kastenbaum (1967), stemmed from the interest in the perspectives of the elderly as a group growing in proportion in society.

The focus on the patient as unique was reflected in studies of styles of dying, different styles being related to personality and to life experiences, particularly the social (McCoy, 1974; Keleman, 1974). Death began to be seen not only as a biological phenomenon but a psycho-social one as well, when, as so often happened, the dying were cut off from social reality and became the 'living dead' (Keleman, 1974:63). Many of the sociological and psychological studies came from the United States; in Britain, Hinton (1963) was exploring the meaning of dying for patients in
terms of the physical as well as the mental distresses that they experienced, and observing the relationships between the two.

This was a time when new theoretical insights and methods in sociology, for example that of Symbolic Interactionism (Blumer, 1962), and Grounded Theory (Glaser and Strauss, 1967), were being used to illuminate meanings in social interaction in ways that were not open to a more functionalist approach. Strauss and Glaser’s (1977) study ‘Anguish’ based on observation of the last weeks in the life of a patient, bring home most forcefully the physical, psychological, financial and social distress that she and her family suffered, and the part that interaction with those around her played in this. It would seem that both subjectively and objectively her quality of life would have been assessed as very poor. Although this was one case study only, elements of this situation will be recognised by any professional conversant with terminal care.

One very important aspect of meaning in the care of dying patients is the meaning the situation has in terms of prognosis and whether this is consistently shared by all involved. Glaser and Strauss (1965) used participant observation techniques to identify different awareness contexts, ranging from ‘closed’ when the prognosis was kept hidden from the patient, to ‘open’ when this was shared by all concerned. These new concepts were particularly helpful in the clinical field in that they helped to open up the subject for discussion and further research, highlighting its complexities and the part that the interaction of all concerned played in creating and maintaining awareness context situations.
Another aspect of dying is that it is a dynamic process; research has focused therefore upon the 'dying trajectory' seeking to observe pathways and patterns in the physical and psychological changes that occur. Dying trajectories have been studied in relation to changes in the disease process and the organisation of care (Glaser and Strauss, 1968; Pattison, 1977) but most particularly in relation to the emotional responses of the patient. In 1975 Parkes stated:

'Several studies now indicate that psycho-social transitions follow a pattern which is not completely predictable but which is sufficiently consistent for us to begin to plot its course'. (P. 2)

This course has been observed to contain a variety of responses. Kubler-Ross (1970) used a series of unstructured interviews to typify these as denial, anger, bargaining, depression and acceptance. She suggested a progression but was more flexible about this than the understanding of some of her readers. Her influence has been very great in drawing attention to emotional reactions; when Downie visited a variety of settings for terminal care in the United States, there was only one institution in which people did not ask her if she had read Elizabeth Kubler Ross' findings (Downie, 1974).

Glaser (1966) sought to formulate a descriptive model for understanding emotional pathways after the disclosure of terminal illness. Patients were seen to respond initially by depression after which the path divided either into denial or into gradual acceptance that took the form of fighting, or of active or passive preparation for death. Welshman (1972)
looked closely at 'denial' and noted a progression within this response, which was designated into three orders. His work contributed much to the growth of a new conceptual framework with concepts such as 'Middle Knowledge' or the area of uncertain certainty between open acknowledgement and utter repudiation. (P. 65)

The deeply subjective individualistic approach of much of this work in the last two decades was part of a general trend to consider the situation from the point of view of the person experiencing it. This was also seen in quality of life studies (Rodgers and Converse, 1975). These various studies on the distress, the meaning and the individuality of dying had a real relevance to health care professionals in understanding their patients and themselves in their interaction with patients. and in formulating new aims of care.

However, influential ideas for better patient care did not only spring from specialist fields but from general trends that were part of the range of ideas of the day. Early on Henderson wrote (1960)

'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 a peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge.' (P.4)

The work of Maslow (1970) was to influence many professionals to think in terms of their patients as having a multiplicity of inter-related needs. In nursing there was an important trend to devise models of care that
centred upon the patient as a 'whole person' with psycho-social and spiritual needs as well as those that were physical. This approach was incorporated into theoretical models of care in which systematic assessment of need was to be achieved through the assessment phase of the 'nursing process' (e.g. DHSS, 1981; Roper, 1983; McFarlane, 1985). A particular emphasis was that these needs should be met as far as possible according to the wishes of the individual concerned; nursing was seen as the mutual satisfaction of needs between nurse and patient (Chapman, 1976).

The Hospice Movement Develops

Thus, general trends and a growing body of specialist research highlighted gaps in care, and explicated the physical and psycho-social needs of the dying patient and of his family, influencing the hospice movement as well as stimulating an interest in it and in the spread of its principles in the wider field of terminal care. Perhaps one of the most important effects was that this body of research provided new theories and concepts and gave health professionals working in a field fraught with difficulty, a new confidence upon which to base their work, and therefore a new willingness to engage in it.

Another important influence in the spread of hospice type principles was that the hospice programme was seen to have remarkably positive results in terms of improved quality of life for the patient. This achievement helped to change professionals' understandings as to what could be done and provided a new set of standards to meet. The impact of this new awareness, the firing of imagination, is expressed by Smyser (1982) who
recalls a visit to St Christopher’s Hospice in 1977 when he contrasted the experience of the patients there with that of some of his friends who had died in receipt of the latest technology. He said of St Christopher’s:

'This was a home for the dying yet what we saw was people living.'

and of his friends’ experience:

'machinery, emaciated baldness, tubes ... All dressed in white open backed nightshirts that wrest away all personal dignity. In America today we still handle death badly but we are doing it better than in 1970. One reason that we are handling it better is the hospice movement.' (P. 1260)

It was not surprising that from the early days the emphasis was on 'quality of life' for the patient, for people released from extreme physical and emotional distress were seen to be free to engage to a much greater degree in those aspects of living that were important to them; thus this phrase neatly encapsulated the new vision for terminal care. Moreover this term was becoming popular in other fields, particularly the political (Dalkey, 1972), so that there was a general understanding of its meaning and therefore of the aims which it represented; it was an emotive publicity slogan. However, the concept had a deeper meaning than this for as was decided at an international conference, to work with the dying involved an understanding of living (Pegg and Metz 1981):
'To work with death and the dying is to work with life. To appreciate the issues of death, one must have a sense of, and appreciation for the quality of life.' (P. v)

The concepts, 'quality of life', and 'living' have continued to feature in the literature and research associated with the hospice movement, and in national and international conferences associated with the care of the dying (e.g. DHSS, 1972; DHSS, 1980; Saunders, 1981; Wilkes, 1984). However, the focus on living has never been equated with 'an eat and be merry for tomorrow we die' approach that might seek to force certain styles of living upon the patient. Rather, the focus is on helping the patient do the things he needs to do and would like to do, which, also may include disengaging from life (Pattison, 1977).

Within five years of the founding of St Christopher’s the hospice movement had made a considerable impact; a small number of organisations and Regional Hospital Boards had set up units for the terminally ill, and doctors and nurses were increasingly coming to them for instruction. A Nursing Officer of the Department of Health and Social Security (Jones, 1972:10-11), described the impact of the hospice movement as five-fold, the hospice movement had:

1. Stimulated awareness of the problems and needs of the terminally ill 'helping to make death and dying a respectable topic'.
2. Devised a system and methods of care that differed from, but were not in conflict with, the National Health Service.
3. Demonstrated the importance of the voluntary contribution to care.
4. Reinforced the importance of education and training in improving patient care.
5. Contributed to a change in emphasis from hospital/hospice to domiciliary care.

By the mid 70s in the United Kingdom, there were over 30 homes for the care of the dying. Some of these were charitable and included 12 Marie Curie Homes, and some were funded by the National Health Service (Saunders, 1976); an indication of the wider recognition of their worth. There was also much interest in improving the care of the dying in settings unrelated to hospices. This interest was also being reflected in developments in the United States and in other countries.

New Frameworks

By the end of the 70s, the hospice movement had spearheaded new frameworks for organisation of care, for a basis of expert work with the patient, and for a spirit of care, or quality of interaction. It was becoming acknowledged that 'hospice' was a concept of care rather than a particular institution with beds, and therefore its principles could be carried out in different organisational settings. Recognition of the basis of the work as being psycho-social and spiritual in nature, as well as physical, was coming with the awareness that the patient's pain was associated with every aspect of his life. This formal focus was not enough however, wide though it was, if it lacked a spirit of care that would help to meet some of the patient's deepest needs within the care that was offered, the need for esteem and friendship in the face of loss and the loneliness of dying.
The spirit of care, a quality of interaction has been expressed in
different ways, each adding something to its understanding; essentially it
is a giving of part of the self of the carer to those they care for.
Saunders (1986) refers to ‘hospis’, the original term for hospice, not
only as a place but as a feeling between host and guest, where the guest
is honoured and welcomed with warmth. She uses the empathy derived from
this quality of contact to guide in such sensitive situations as how and
when to impart bad news (Saunders, 1976). Palouzi (1983) refers to hospice
as an atmosphere. Pattison (1977) sees helping as not so much doing as
being. Schneidman (1976) and Feigenberg (1980) conclude that the task of
the clinical thanatologist is to be a friend.

This century has seen the blending of many strands from the past as well
as the present in the care of the dying, the mixing of principles derived
from early models of care with the scientific derived from later
centuries; and to this have been added other strands, the religious, the
humanitarian, voluntary and community effort, and charismatic leadership
in the work of individuals. All have contributed an excellence of this
time, to the development of the modern principles of terminal care. The
hospice movement is therefore, not only a child of the present but also of
the beliefs, customs and ideals of the past.
It is now over two decades since what is frequently known as ‘the modern hospice movement’ was founded, and as has been discussed in the last chapter its impact has been considerable throughout the world, leading to increasing awareness of the need for improvement in the care of the dying. However, anyone working in this field, particularly in the teaching unit of a hospice, would empathise with Sue Hawketts heartfelt concern (1986) that the concepts of hospice care have either not been fully understood, or have met with disapproval in some hospitals, for in a teaching situation one hears distressing accounts of the experiences of patients and staff, and encounters lack of understanding of the principles of modern terminal care.

As part of this research project 344 nurses, two-thirds of whom were in training, were presented with a brief questionnaire when they attended St Joseph's Hospice for an educational session, and asked to complete it before the session commenced. The nurses came from 17 different educational centres, and data was collected from nurses attending 24 educational sessions (Appendix 4). Table 3.1 (next page) indicates their response to the question, "Our visitors to St Joseph's Hospice have many different areas of interest - tick those areas where you feel some exploration in depth would really help you in your work". This shows considerable need for education and support in all the main areas of terminal care, and awareness of this need by trained as well as student nurses.
Table 3.1 Aspects of Terminal Care and Expressed Educational Needs.

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Student Nurses (n = 233)</th>
<th>Trained Nurses (n = 111)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients emotional needs</td>
<td>n 199</td>
<td>% 85</td>
</tr>
<tr>
<td>Relating to patients</td>
<td>n 192</td>
<td>% 82</td>
</tr>
<tr>
<td>Symptom Control</td>
<td>n 119</td>
<td>% 51</td>
</tr>
<tr>
<td>Bereavement Care</td>
<td>n 105</td>
<td>% 45</td>
</tr>
<tr>
<td>Physical Care</td>
<td>n 87</td>
<td>% 37</td>
</tr>
<tr>
<td>Home Care</td>
<td>n 50</td>
<td>% 21</td>
</tr>
</tbody>
</table>

* Percentages do not sum to 100% as most nurses expressed several needs.

Simms (1984) said of promoting the principles of terminal care within the National Health Service, that there was an enormous educational job to be done. This chapter explores the efforts to promote good terminal care through hospice development, and through palliative care units, and support services in hospital and community.

THE HOSPICE AND ITS PROGRAMMES

The most obvious medium for the spread of hospice principles, would seem to be the development of hospices or hospice type programmes. However, as far as the former is concerned it is unlikely that such development would ever provide the main answer to the needs of the wider population. At the moment from a purely numerical standpoint it cannot, for hospices are
insufficient in number, and unevenly distributed, with a greater proportion in the South of Britain. (Smith, 1985). Wilkes (1986) noted that hospices were able to care for some 35,000 patients a year, only approximately 5% of all deaths. At present there are 147 hospices in the United Kingdom with 2,600 beds (The Hospice Information Service, 1990). Hospices continue to increase in popularity and cannot cope with all the demands of cancer patients let alone those of other dying patients who could benefit from the quality of care offered.

One barrier to the setting up of new independent hospices is that of finance. It is hard enough to find the capital but harder still to keep the organisation running year after year, when the stimulus to create has faded from the public mind. Because of this precarious situation association with the National Health Service would seem to be a good thing, but this is not without its problems especially when it results for the hospice in some loss of control over its work. The hospice may not be free to chose the patients it feels that it can help best, and may experience other constraints.

Whilst as a teaching unit the hospice must expect to educate and imbue other professionals with its spirit, it is the proportion of those others, to its own especially selected and self-selecting staff that matters, if it is to achieve this aim, otherwise the hospice may become infected, if only in subtle ways, with the problems and attitudes in terminal care that the hospice movement has sought to correct. These conditions are a potential threat to all its principles of care. Conversely without close co-operation with the NHS, the hospice may not be
able to attract to its staff able and suitable professionals because it is not closely enough allied to National Health Service patterns of career development for the experience it offers to be recognised as part of their training, and for them to feel they may return to the Health Service at some later date without loss of salary or status. These problems are being addressed as part of hospice development.

As part of its development the hospice has also to continue to build up and manage a team of carers under leadership that creates a facilitating atmosphere for patient and staff alike, in particular new hospices have to develop their own management styles. At the beginning the movement benefited from strong charismatic leadership; now that the founding generation of individuals are beginning to retire it faces new challenges in the creation of new styles of leadership with a greater emphasis on team management of an inter-disciplinary nature. Whether it is in the ward situation or at management level the achievement of 'a place where ... there is no hierarchy of importance in what is done' (Saunders, 1965:2) is not easy for this is contrary to traditional medical thinking. As part of a wider professional society the hospice is not immune from the conflicting ambitions and power struggles that exist between health professionals in other settings; and indeed may be more at risk in this area because it tries to forego tradition and rigid structure. These are problems that are not easily or quickly overcome.
Another problem can be retaining staff for long periods of time, for to care for the dying is to experience repeated loss. Mount (1986) expressed the problem:

'To live is to experience loss. To practice oncology, whether as a physician, nurse, or other member of the care-giving team, is to augment our losses, many-fold, for they are an integral part of our professional existence. Moreover our losses do not occur in a vacuum. They interact with, modify, and often augment the other stresses in our personal and professional lives. Our reaction to loss may be repressed, only to surface later, associated perhaps with some unrelated event'. (P. 1127)

Saunders (1986) saw the ability of staff to continue to practice efficiently as related to the ability to cope with the pain within themselves. She saw that much support was needed and a long period of adjustment to this type of care if carers were not to emotionally withdraw from patients.

Another problematic issue for hospices is how they should limit their services, for demand is great and they frequently have to deal with the pressure of waiting lists - patients' admission has to be delayed or they have to be turned away. Quite frequently at St Joseph's people on the waiting list died before they could be admitted. Another problem as far as meeting the needs of the wider population of dying people is concerned is that admission is largely restricted to cancer patients, although some hospices such as St Joseph's, do have limited beds for those dying from
other chronic diseases. Patients with other diseases also suffer distressing symptoms that need expert care to control; there has been some pressure for hospice care for AIDS patients for example.

In an effort to help as many patients as possible many hospices offer admission for symptom control and respite care, both of which are expected to be temporary, and 25 - 40% of first admissions do result in discharge (Redmond, 1989). This is not the case at St Joseph's where few patients were able to return home; for many were admitted with social problems as well as the medical problems of the disease. However, it has been found in some hospices that when the patient is deemed able to leave then there may be other problems to face, one of them being the distress of patients and families who feel unable or unwilling to shoulder the burden of the disease, without the degree of support that they have become used to; although they may well be offered a hospice directed home care programme. Here the high quality in-patient care had a 'cocoon effect' making patients reluctant to leave (Twycross, 1986).

If patients are unwilling, or unable to go home with domiciliary support then, Redmond (1989) states from her research with several hospices, 'other accommodation has to be found', although this is not always possible. In its dilemma to keep its beds for those who are objectively defined as most needing its services the hospice is forced into a situation of seeking to fit the patient to a care category and a wider social situation, rather than the care to the subjectively defined needs of the patient as an individual, and the family as part of the unit of care. This runs somewhat counter to cherished principles and can be a
source of role stress for staff. This is a situation in which advances in quality of care have heightened expectations and created awareness of new gaps that might be filled; the proposed answer to pressure of demand at the present is selectivity with attempts to structure the expectations of all concerned to the reality of a situation of dealing with infinite demand and finite resource.

This theme of gaps in care is taken up by Saunders and McCorkle (1985) who find that the characteristics that make hospices and hospice programmes in the United States, so effective for some, limit its accessibility for others; one of these characteristics being limitation of services to those with a life expectancy of 3 to 6 months. Saunders and McCorkle suggest that the period of vulnerability for patients starts long before this, and at this time suitable care is not always available. Applying Pattison's (1977) trajectory, his living - dying model to the situation, they state that a need exists for a model of care that will address more of the living phase, encompassing hospice and alternative programmes of care. Bates (1985b) affirms the need for earlier rather than later care stating that 50% of cancer patients need palliative care from the time of diagnosis.

However, there are many reservations about the use and development of hospices, one is that they cannot suit all patients. For example, in a small pilot study based on interviews with nurses engaged in terminal care, Simms (1984) found that for some working class patients the quiet and air of purity was rather oppressive, as was also the constant contact with those who were dying, they preferred the cheerful bustle of the
hospital. Another reservation both in and outside of the hospice movement, is that with a proliferation of hospices there is no guarantee that the term 'hospice' will automatically be associated with quality of care; for there is no overall regulatory body that can impose standards to maintain principles (Taylor, 1983).

Other reservations spring from the view that professionals have of their role and of the services that they could or should offer. Some fear that patients might accept the palliative care of the hospice, or of a hospice type programme, too readily, or refuse experimental drug schemes, thus denying themselves a chance for cure or prolongation of life. Adams (1984) states:

'...the identification of the point at which a patient is perceived as being hopelessly ill or irretrievably in the dying process is extremely difficult. All of us - the patient, the family and the physician - may perceive this point differently' (P. 14).

Referral to a hospice, unless it is for purely social reasons, is also tantamount for some doctors to an admission of failure on their part, and they may refrain from using the hospice for this reason (Wilkes, 1982). For others, referral to hospice care is seen as a negation of deeply felt professional responsibility, as Smithers (1973) stated:
'I confess to a prejudice against isolated terminal care homes; not the few expert, specialist institutions for the really difficult problems, for research and development, for teaching ... but for the general run. When you take on a cancer patient you take on his problems. Cicely Saunders ... her teaching must be put back into the hospitals where the patients are. We should turn to her when beaten, not for every day. (P. 34)

Thus, there are many cogent reasons why the spread of hospice principles, through direct hospice services, is limited, and why there is some consensus of professional, if not public, opinion that there should not be a proliferation of hospices, but that certain hospices with a full range of services, including home care, bereavement support and teaching, should stand as models of excellence and purveyors of these principles, whilst the rest of scarce resources should be directed towards improvements in home care and hospital services which together are responsible for the vast majority of dying patients (Tiffany, 1983; Simms, 1984; Taylor, 1983). This view was re-iterated at a more recent major conference (DHSS/NAHA, 1985), where it was recommended that each Health District should have a specialist service derived from partnerships between voluntary services and the National Health Service, to provide advice on symptom control for patients with terminal cancer, high quality nursing care, spiritual support for patients and their families, and bereavement care. In this way the principles of good terminal care were to be disseminated and applied to those dying at home or in institutions outside the hospice movement.
DISSEMINATING HOSPICE PRINCIPLES TO OTHER SERVICES

Since 'hospice' is a concept or a programme rather than an institution with specialist beds (Walker, 1981) a major drive of recent years has been to endeavour to promote the principles of terminal care in hospital and the community. A variety of measures have been undertaken, with funding at least partially provided by voluntary bodies such as the National Society for Cancer Relief - conferences have been organised, professionals with specialist skills placed in key educational posts, palliative care units developed, and support given in hospital and community. Some of these mechanisms for disseminating hospice principles will next be discussed.

The Palliative Care Unit

The palliative care unit is a unit developed in a hospital setting, in the grounds, a ward, or part of a ward, which has special facilities for the terminally ill. It provides care for patients, using expertise in symptom control, and often provides an educational and advisory service for other professionals. The palliative care unit has many of the characteristics of the hospice - a more restful, relaxed and homely atmosphere than the acute ward, and provision for meeting the psycho-social needs of patients and families.

However the palliative care unit faces similar problems to that of the hospice in that it is easier to raise the initial funds for development than find those to meet the running costs. Other problems stem from its close association with the hospital. Consultants from the hospital may see it as a 'dumping ground' for incurable patients, its staff may be part of the general system of staff deployment and subject to pressure of
shortage. At a national conference (DHSS/NAHA, 1985) it was noted that of the 16 hospice units within the NHS only one had two consultants and all had fewer nurses than equal units in the voluntary sector. Moreover some of the staff who are directed to work in the unit, perhaps as part of training may not necessarily have chosen to work there (James, 1986). Inasmuch as adequate levels of staff, well oriented to the care of the dying, are important to maintaining the principles of terminal care these factors influence the service that can be offered and the stresses under which staff work.

The Hospital Support Team

One important method of beginning to apply hospice type principles of care in the wards of traditional hospitals has been to set up a specialist team that operates within the hospital (Bates and Hoy, 1981; Dunlop and Hockley, 1990). A small support team, usually consisting of two or three nurses and sometimes a doctor, is there to provide advice to all those caring for dying patients anywhere in the hospital, but not to take over responsibility for care. The support team may also supply advice in the local community. One big advantage is that its advice is available for all dying patients.

The purpose of the support team is to adapt the insights and therapies developed in hospices to the hospital environment. Dunlop and Hockley (1990) list the four main aims of support teams. The first aim is to assist relief of distressing symptoms, and to give emotional, social and spiritual support to patients who have a terminal illness. This seeks to meet the need for better symptom control and psycho-social care in
hospitals (Wilkes, 1984; Parkes, 1985), The second aim is to provide counselling and support to relatives and the bereaved, a major principle of terminal care being the care of the patient with the family. The third aim is to provide support and advice to staff caring for the patients, meeting the needs of staff who experience much stress in caring for the dying (Mount, 1986; Hockley, 1989; Webster, 1981; Whitfield, 1979). The fourth aim is to take part in education programmes on a multi-disciplinary basis. Support teams therefore seek to meet the problems associated with poor terminal care. These are comprehensive and daunting aims if the size of a major hospital and its educational programmes are considered.

Support teams face many difficulties; some of the problems of translating hospice type principles into other settings are indicated in Walker's (1981) comparison between hospice and traditional care. Although this is American much applies to this country. Major differences were found on several dimensions - (1) the traditional attitude to death was one of denial, silence and conspiracy whilst in the hospice patients and family were encouraged to come to terms with reality; (2) the traditional treatment goal was prolongation of life compared with that of comfort in the hospice; (3) limited amounts of medication were traditionally given for symptom control because of the fear of dependency, while in hospice care this was not so, and (4) traditionally there was little support for the family or education in terminal care, whilst in the hospice programme these were a major emphasis. These findings indicate the very sensitive nature of the tasks of the support team, which may only work by request of those whose attitudes and orientation may be very different to their own.
With all the problems, it is not surprising that support teams have developed slowly and often with great difficulty. The first was instituted in 1975 in the USA, at St Luke’s Hospital in New York; this was shortly followed in 1977 by the first support team in Britain, at St Thomas’ Hospital (Bates and Hoy, 1978). They were able to demonstrate their effectiveness for after appropriate symptom control some patients were able to be discharged home. Support teams in hospitals increased to 38 by 1989, but during this time five had collapsed (Dunlop and Hockley, 1990). The problems encountered included a misunderstanding of their purpose, some consultants seeing the job of the team as to refer patients to hospices so as to free beds, failure in funding, failures in communication (Herxheimer, 1985), doctors and senior nursing staff who found it difficult to ask for, or take advice, particularly when it came from a nurse and involved prescribing, difficulties that the team sometimes had in controlling symptoms, especially when these were side effects of treatment, and the reticence of some patients to discuss problems when they felt this might offend the hospital staff responsible for their care.

The effectiveness of one very well established team was demonstrated by a group of young nurses who attended the hospice for an educational visit. They spoke very highly of the support that they received from the nurse on their hospital team. She was available to anyone and requests for help did not have to be channeled through senior staff. This service helped to reduce their stress and enable them to continue to relate positively to the patient. Such schemes have great potential for staff and patient; if they can survive they may find themselves increasingly supported as attitudes slowly change.
The Community

Many hospices have home care teams of nurses who can help to look after patients in their own home, but not supplant the community nurses in attendance; there were 25 such teams in 1985 (Bates, 1985b). Provision may also include a day centre and other support; for example, St Joseph's hospice had a day centre and also certain beds that were reserved for the home care patients when the family needed respite, or when they could cope no longer. Today there are 115 day centres in the United Kingdom, either free standing or centred within a hospice (The Hospice Information Service, 1990).

As stated previously community services are served in some areas by hospital support teams, others have teams of specialist Macmillan nurses to whom they can turn for advice. There are now over 600 Macmillan nurses working in the community; being initially funded by the National Society for Cancer Relief and later taken over by the Health Authority. Hospital and community based support teams totalled 93 in 1985 (Bates, 1985) and today total over 250 (The Hospice Information Service, 1990).

The community based support teams, which may comprise only one or two nurses, face many of the same problems as the hospital team. It is not easy to make effective work relationships with those who may feel threatened by your presence, and some General Practitioners do not take kindly to the advice of nurses, nor always do nursing colleagues; much diplomacy and patience is needed. There are also problems more specific to the community for if advice is to be put to good use nurses working in the community need adequate staffing levels and really adequate back-up
services, and both are in very short supply in many areas. These back-up services include laundry services, Home Helps, and night and day sitting services to provide the family with relief but they are not uniformly or sufficiently available to cancer patients let alone others.

Home care assumes that the patient has family and friends to care, and that they will be able to care. Until the situation is personally experienced it is perhaps hard to imagine the degree of help that may be required to fully support a very heavy, dependent, immobile, and perhaps incontinent dying patient at home for any length of time. The nursing services are very stretched to visit twice a day and it may be that within a few minutes of their departure the patient will have shifted or become incontinent (even the best of devices are not infallible) and the whole nursing procedure will have to be started again without the formal help. Moreover, the amount of equipment that will be needed in the home will be considerable, particularly if it includes a lifting device which may also be in short supply. Doctors and nurses must have their time off and cover may be insufficient, the relief worker may be unacquainted with particular problems, or unable to note any change in condition. Under these circumstances, even with the seemingly considerable amount of help that can be given the family may at crucial times, feel very much on their own, both physically and emotionally, and the stress is compounded when the carers are elderly. Wilkes (1982) found that a quarter of cancer patients dying at home were cared for by next of kin aged 70 years and over. In this situation when help is insufficient collapse of the family may eventually occur, to be followed later by heightened guilt and grief at the thought of ‘failing’ the patient.
All this is not to decry home care with its great potential for meeting the needs of patient and a family who wish to try to cope, but to note that a great deal must continue to be done to provide adequate support for all concerned. In a retrospective study of two groups of 30 patients who had been cared for by a skilled community team, one group eventually needing institutional admission, Woodhall (1986) found that the main factors affecting the final place of care were the health of the home carers and the degree to which good symptom control could be obtained at home. She concluded that skilled nursing care in a relaxed atmosphere, although institutional, was necessary to meet the needs of some. Doyle (1981) noted that only 30% of home care patients in Edinburgh died at home, admission had become necessary because of the stress on relatives, insufficient nursing staff, night-sitters or equipment. Parkes (1978) found that according to surviving spouses, 28% of a sample of over 200 patients had experienced severe or mostly unrelieved pain at home and concluded that home can be the best or worst place to die. These and other studies suggest that if home care is to be universally viable, and the principles of terminal care put into practice, then much greater resources must be put into this service in addition to specialist advice. Nurses must be given the tools with which to work, and the family those with which to care.

The foregoing discussion indicates that it is not easy to disseminate hospice principles into other settings; this may require from other professionals the relinquishing of cherished principles, and changes in attitudes to dying, as well as different organisational provision.
Adapting hospice principles in other places - medical students' perceptions

As part of this project some research was undertaken with seven medical students gaining elective experience at the hospice. They were asked what differences they perceived between the hospital from which they had come and St Joseph's hospice (Appendix 5). Table 3.2 indicates some broad differences:

Table 3.2 Medical Students Perceptions of the Difference Between the Hospice and the Hospital n = 7

<table>
<thead>
<tr>
<th>Hospice compared with Hospital</th>
<th>Number of Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>More friendliness between staff and between staff and patients</td>
<td>7</td>
</tr>
<tr>
<td>More time to spend with patients</td>
<td>6</td>
</tr>
<tr>
<td>More family involvement</td>
<td>3</td>
</tr>
<tr>
<td>Better multi-disciplinary teamwork</td>
<td>2</td>
</tr>
<tr>
<td>Better support for staff</td>
<td>2</td>
</tr>
<tr>
<td>More of a psychosocial approach</td>
<td>2</td>
</tr>
<tr>
<td>More acceptance of death</td>
<td>2</td>
</tr>
<tr>
<td>Patients have more control</td>
<td>2</td>
</tr>
<tr>
<td>More emphasis on living fully</td>
<td>2</td>
</tr>
</tbody>
</table>

Many of these differences would be hard to eradicate for as Student B suggested, some such as staffing levels, depended upon economic forces not under the immediate control of those closest to the patient. He also felt that at the hospice those nurses that were available, could give more time to the dying because they were able to concentrate on them alone, rather than having to meet the needs of the dying alongside those of patients undergoing surgery or medical investigation:

"The most striking difference - every person who is working here has more time to care for the patient ... for the doctors and nurses in my
country it is a question of time because of economics - they are very much under stress in general hospitals’.

The inter-disciplinary differences also challenge much in the tradition of hospitals, with its strict hierarchies within disciplines, and between disciplines. In hospice care, professionals must work closely together to achieve the most for patients:

Student G. ‘There must be hidden conflicts here - but as far as I can see people seem to work together and there is not the heavy professional medical status here - the consultants are not up on a pedestal. It could be partly (the friendly) ward meetings, but I don’t think that it is this so much but the way people relate in their everyday contacts. You find ward meetings elsewhere - for example in psychiatric hospitals. The ward meetings are the cherry on the cake but what is important is the general atmosphere’.

As is noted in chapter 7 another student felt the difference was in the hierarchical system within the medical discipline and this hindered effective symptom control. Two students noticed a difference in the control that patients and families had in the hospice. For example:

Student C ‘Visitors come and go as they like - can give as much or as little care as they like - visitors in my hospital are not allowed to do anything - feel they can’t ask for a glass of water or make suggestions to doctors - here visitors are free to make suggestions to the doctor’.
Student E 'There is respect to the person and dignity and patients have control'.

This is very different from the traditional hierarchy in which patients come at the bottom of a long and rigid chain of command. Dunlop and Hockley (1990) quote Rule 7 of St Bartholomew's Hospital Rules published circa 1900:

"every patient must strictly obey the Directions of the Physician or Surgeon under whose care he or she may be placed". Compliance was ensured by the concluding rule; "any patient acting contrary to the foregoing Rules will be reported by the Sister of the Ward to the Steward or Matron, and by them to the Treasurer: such patient will be admonished or discharged". (P. 51)

Although for several years there has been some emphasis in hospitals on increasing patient participation in decisions, and nursing has recognised the patient's right to control (e.g. Henderson, 1960), there is still much of this tradition that remains, even if it is diluted; power over the patient can be exercised in subtle ways by all concerned (Thomas, 1990). The comments of these students affirm this.

Student B thought it was also a difference in attitudes to death, there was more acceptance of death in the hospice:

'Dying in a hospice - you keep him (the patient) here in his bed - in my country patients are put in a single room and the curtains closed'.
The few differences that have been discussed here indicate that it is not at all easy to adapt all hospice principles to the general hospital, for this cuts into deeply held attitudes and vested interests. Two students were asked if they thought that hospice principles could be translated into the general hospital. Both thought so but with reservations. Student B thought that change might eventually be brought about through the pressure of professionals who were dissatisfied with the present situation:

'Yes, because it is a thing of behaviour - of attitude - you sometimes talk to nurses in general hospitals and they find their jobs a disappointment - always in hurry - not so many nurses and not so much personal contact with the patient - they say all we are doing is something for physical treatment but we don't have time for emotional work - it is the same for the doctors'.

Student D 'I like to think so although it would take time and a huge restructuring. I am not against general hospitals - hope to spend my career in one'.

These comments are encouraging but it has to be remembered that they came from those who had elected to have hospice experience and therefore were especially likely to be open to hospice principles.

CONCLUSIONS
To return to Sue Hawkett's heartfelt concern (1986) that the principles of terminal care were not being applied or understood; in the face of all the
deep seated difficulties it is perhaps surprising that so much positive change has taken place. A hospice teaching unit may receive several thousand visitors a year but cannot possibly hope to give more than a few hours to each, mostly in a lecture hall setting; it may then make more lengthy arrangements for the more senior and influential. To many professionals from other settings the focus on 'what we do' may seem unrealistic, too different, when they do not have the power to alter the forces that dictate their work. It may also seem not all that appropriate to some of their dying patients, and it has been suggested that 'hospice' is not for all (Simms, 1984; Jacobsen, 1984). As has been recognised, a great deal of adaptation is needed and this is not easy; for providing advice and support in the hospital and the community takes time to develop and meets with many difficulties.

There does however seem to be a general consensus amongst professionals that whether or not they fully understand hospice principles, what they want for their patients, even if only vaguely, is as much happiness, or quality of life, as is possible in their last days. This gives reason to believe that research focussed on dying patients' perceptions of what quality of life means for them would assist professionals engaged in terminal care. This is the main aim of this study - to identify factors that are important to the quality of life of dying patients. It is hoped that the findings will assist the effort to bring good care to these patients. It is hoped moreover, that the qualitative approach adopted will portray the patients feelings about their situation in their own words - thus providing an experience of learning from the patient, likely to boost empathy and motivation. For the patient source, was after all, the
motivating basis of the founding of the principles of modern terminal care.
SECTION II

QUALITY OF LIFE
The concept 'quality of life' has a very long history of general usage for as an evaluation of life as a whole it was discussed by Socrates in the context of quality versus quantity of life (Cohen, 1982). It has been investigated by philosophers over the ages, but it was not until this century that it became a phrase of common parlance, particularly with regard to political situations. For example, in 1970 President Nixon stated in his State of the Union Address to Congress:

'Our purpose in this period should not be simply better management of the programs of the past. The time has come for a new quest - a quest not for a greater quantity of what we have - but for a new quality of life in America'. (Dalkey, 1972:85)

In 1972 the term had become so popular that the comment was made that the 'quality of life' phrase had almost supplanted the terms 'happiness' and 'welfare' in general discussion (Dalkey, 1972). This popularity seems to have increased for Szalai (1980) comments:

'The term has a world-wide popularity: "Qualite de vie" is as much on everybody's lips in France as "Qualitat des Lebens" in Germany, "kachestvo zhizni" in the Soviet Union, or "az elet minosege" in my own little country, Hungary'. (P. 7)
However the general appropriation of a rather catchy phrase is a far cry
from being able to incorporate it into rigorous research, and perhaps it
would not have gone on to be used in a scientific way but for the
understanding that people have an integral judgement about their lives and
are able to sum components, order priorities and engage in trade-offs
(Dalkey, 1972). Szalai (1980) documents the use of everyday questions such
as, How are you to-day?, that at least to some extent require this form of
ability, back to the fourteenth century in England, and found that similar
social questions were found in many countries, including France, Germany,
Italy, Russia, and China. Built into social language there are also polite
forms of reply such as 'fine', to limit response or fend off unwelcome
intrusiveness, but Szalai (1980) contends in defence of the use of the
quality of life question in research that the long and wide existence of
this form of query stems from the ability of humans to understand what is
meant, and to provide an answer consistent with what is being asked:

'the willingness... and capability of human beings to keep in evidence
the life they are living, the conditions of their existence and ...to
form an integral judgement about their life' (P. 11)

The likely understanding of the quality of life phrase has provided a
basis for a large, and growing field of quality of life research, a
speciality of social research in its own right, which finally achieved
recognition in terms of inclusion in social science encyclopaedias in the
late 70s (Szalai, 1980). Subsequent research has drawn heavily on some
early major studies stemming from North America (e.g. Bradburn, 1969;
Andrews and Withey, 1976; Campbell, 1976). These explored the concept,
often with large samples, and defined it as a measure of 'satisfaction', 'happiness' or sense of 'well-being', with life: and these terms have been found to correlate moderately well with each other (von Kerekjarto, 1982). Researchers have identified such variables as income, youth, education, marriage, participation and positive feelings as correlated to happiness, concluding that while these and other variables must be divided and sub-divided into their component parts, the quality of life phrase itself is best treated as indivisible. (Szalai, 1980).

In their philosophical exploration of the concept of happiness Shin and Johnson (1978) found that happiness had many connotations. It was associated purely with material possession - having enough of pleasure producing things - an Epicurian concept - it could also be viewed as a general contentedness that sprang from an equilibrium between satisfaction and desire- a broad Utilitarian concept, or in accordance with the thought of Aristotle it could be narrowly focused on self-fulfilment in creative activity. There are thus as many possible aspects to happiness as there are to life - quality of life is a most complicated multi-faceted concept.

Some of the problematic issues in all quality of life research also stem from the relationship of quality of life to needs, and thus to the complexities of needs theory, for as Marshall (1973) states:

'Need is a universal factor, part of the normal functioning of an organism or social unit. The cycle of need through to satisfaction is a condition of life'. (P. 6)
Needs theory indicates that need may be subjectively or objectively defined (Bradshaw, 1972), for the needs of the individual are set within a social context. Quality of life enquiry wrestles therefore with the problems of objectivity versus subjectivity not only on methodological grounds but also on the ethical and philosophical. Another issue in needs theory is that of priorities amongst needs. Apart from a hierarchy of broad categories, the survival needs usually being basic (Maslow, 1970), there is the general experience in life of competing needs, both within the individual, and between the individual and others - attainment of one need may require abandonment or deferment of satisfying another. Dalkey (1972) realistically sees quality of life factors as 'trade-offs' between priorities. The social nature of health care determines that one type of trade-off is between the sick and society as provider. As Gerson (1976) suggests quality of life must be viewed as a bargaining process both at individual and society level. Quality of life outcome is the result of the interaction between the two.

Parson's (1951) concept of the 'sick role' is a well-known exposition of one social trade-off in sickness, in which the required release from the endless forms of exchange created by the social norm of reciprocity, inherent in roles and duties, is granted in exchange for certain behaviours upon the part of the individual concerned. This is best seen in the patient with a short acute disease. The patient will need to be excused the obligation to work and to undertake commitments to friends and family, and to become the recipient of their care. In return the patient must seek the means to restoration of health and comply with these means. Thus a patient needing surgery will, unless it is very minor, be required
to accept temporary divorce from social contacts in becoming hospitalised, and in so doing accept the treatment, restraints and conditions that this implies. This situation involves a sharp change of priorities for the time being, with deferment of gratification of other needs. At the same time the patient will receive professional services and perhaps visits and gifts from family and friends and will not be required to reciprocate, except when at some future occasion the positions may be reversed. The situation is one therefore of a temporary giving much less and accepting much more: the sick role is a contingent role and avoids the stigma of social dependency (Spicker, 1984).

Turner (1987) states of the social service given to patients:

'We can regard all forms of social service as systems of exchange because the norm of reciprocity is based upon the notion that there is no such thing as a free lunch, dependency is only acceptable where it is a contribution for previous contributions or where it is in anticipation of a future contribution.' (P. 122)

The patient with acute appendicitis can accept the sick role bargain in the knowledge of an eventual return to normal living; but as many writers have suggested (e.g. Murcott, 1981) it is doubtful whether all the characteristics of the Parsonian 'sick role' are appropriate to the chronically sick or dying. Such patients have no hope of full future reciprocity and may wish while receiving care, to give more, and accept and comply less than is required. In the meanwhile in view of the importance of reciprocity, without which there is loss of social power.
(Dowd, 1980), with subsequent loss of self esteem, it would seem important to quality of life that a different bargain with society be engendered. Levine and Kosloff (1978) suggest:

'We believe we now need to leave the Parsonian formulation in the background ... and to discover new dimensions in the patterned life of the sick person'. (P. 339)

Another important issue centres on the factors that influence the assessment of need - social expectations, values and reference groups (Merton and Kitt, 1950; Runciman, 1966). Hornquist (1982) sees needs as part of a dynamic spiral that changes with internal dynamics, interaction with the world around and expectation derived from increasing individual freedom of choice; therefore expectations and time become an important variable. For example time of life, Engquist (1979) who undertook research with elderly people, noted that:

'Quality of life is not a fixed set of circumstances but rather consists of variables that have changing values for individuals during their life time'. (P. 97).

The width of needs theory therefore imposes a breadth on quality of life enquiry over and above the complexities inherent in the concept of 'happiness', and results in a variety of quality of life definitions in research. For example Young and Longman (1983) who were interested in three specific factors - symptom distress, social dependence and behaviour
morale, from the patients' viewpoint, chose as their definition of quality of life:

'the degree of satisfaction with present life circumstances perceived by the person'. (P. 219)

In contrast Calman (1983) who was particularly interested in the role of expectations chose as his definition:

'Quality of life measures the difference at a particular moment in time between the hopes and expectations of the individual and the individual's present experience'. (P. 2)

In line with this understanding he proposed that the quality of life of patients with advancing disease might be enhanced if they could be helped to alter their expectations, thus narrowing the gap between expectation and reality.

Shin and Johnson (1978) found in their study of happiness that reference groups and resources were particularly important. In defining happiness they stated:

'happiness is primarily a product of the positive assessment of life situations and the favourable comparisons of these life situations with those of others and the past. The various characteristics of an individual and the resources at his command, such as sex, age and
income, influence happiness mostly through their effects upon the two psychological processes of assessment and comparison.' (P. 491)

Another large area of complexity in quality of life research lies in the problems of measurement; it must be decided how components of quality of life are to be measured, and since many have several facets, some of which may not be amenable to measurement, how appropriate surrogate factors are to be found. This raises the many issues of the reliability and validity of both subjective and objective measures and also of finding the most appropriate objective social indicator. Bunge (1975) defined four characteristics of a social indicator:

'An indicator is characterised as an observable variable, assumed to point to or estimate, some other (usually unobservable) variable. It is then a symptom of something else. An indicator-indicated relation can be functional or it can consist in statistical correlation ... (it belongs) to some sociological context ... it allows one to estimate degrees of well-being'. (P. 67)

Having found an appropriate indicator researchers seeking to compile global measuring instruments must identify and combine a series of quality of life components to form a measuring instrument that must be relevant to the parts and to the whole; aiming to produce an integrated system of interacting variables (Andrews and Withey, 1976). This may also involve weighting of the components one against the other. It is not surprising that the problems are challenging and formidable, and have absorbed the attention of large teams of researchers for over two decades.
This very complex situation has a relevance to undertaking quality of life research in any field. It calls for a variety of research projects that will address different parts of quality of life enquiry; which may add, if only a little, to the whole body of knowledge as well as be used for specific application. The literature of such enquiry is enormous and on a world-wide scale. These background issues will now be pursued more directly as they relate to health care, particularly to that of the cancer sufferer and of the dying.

QUALITY OF LIFE RESEARCH IN HEALTH CARE
Quality of life research has had a growing importance for health care in the last two decades, for example, at the end of the seventies less than 5% of papers in major cancer journals measured quality of life (Bardelli and Saracci, 1978), but interest was growing and in 1981 the European Organisation for Research on Treatment of Cancer set up a Study Group on Quality of Life (EORTC, 1981). At the end of the eighties interest was so great that the Medical Research Council was asked for guidance as to measuring quality of life for this speciality (Maguire and Selby, 1989).

The Aims of Quality of Life Research in Health Care
In the last two decades particularly, enquiry into the quality of life of patients has been seen as a means of answering questions that would not have arisen before some of the medical and surgical advances of this century. For such advance has provided choices in treatment; it has also been able to save life but sometimes at the expense of mutilation or chronic disability such as in some cancer surgery, or with extensive
disruption of normal living as in renal dialysis. Moreover some treatments such as chemotherapy may have extremely unpleasant effects.

Many questions in cancer care centre around choice of treatment and their effect on quality of life; for example, Priestman and Baum (1976) wished to compare endocrine therapy with chemotherapy in breast cancer, Sugarbaker (1982) compared the results of amputation with chemotherapy in bone cancer. In cancer care there has been a particular concern with quality of survival, for example in the research of Jennett (1979) and Danoff (1983). Schmale (1983) compared 104 cancer survivors with a matched sample of healthy individuals and came to the conclusion that even years after a cancer experience its impact is such that individuals feel physically and psychologically vulnerable. McNeil (1981) focused on the trade-off between retaining voice and length of survival in the treatment of laryngeal cancer. Studies such as that of Holmes and Dickerson (1987) have sought to define the relationships between the many components of quality of life.

Another way in which quality of life research has been used is to evaluate the effectiveness of different types of care, Greer (1986) engaged with others in a large scale study comparing hospice care with conventional care in the USA. Since the aim in terminal care is to enable the patient to experience as much quality of life as possible (DHSS, 1972; DHSS, 1985) others have sought to investigate the quality of life of dying patients. Wilkes (1984) took a retrospective sample of 262 deaths and evaluated the quality of life of the last days of these patients. For the same reason
quality of life enquiry also came to the fore in the care of the elderly (e.g. Williams, 1982, Watson, 1982; Thomas and Chambers, 1989).

A recent question that has been formally asked of quality of life research is how scarce resources may be prioritised amongst the seemingly endless demand. Williams (1985) developed the concept of the Quality Adjusted Life Year (QUALY), from the speciality of heart surgery. One QUALY represented one year of healthy life expectancy; a year of less than full health scored less than one QUALY. High priorities in health care were then accorded to activities in which the cost per QUALY was low. This global measure has been criticised on ethical grounds for it is seen as putting a value on peoples' lives, and weighting services away from groups such as the elderly (Harris, 1987). The measure has also been criticised on its methodology, for the judgements upon which the scale is based were taken from a small sample arbitrarily chosen, and have not been shown to bear much relationship to real patients facing real decisions (Maguire, 1989; Mulkay, 1987). It is stated that this instrument with great potential power to effect peoples' lives has already been subject to abuse in the drive to conserve resource, for some doctors have been asked to justify the use of a new cancer drug on the basis of the QUALY alone, without reference to data from patients and relatives (Maguire, 1989).

The Issue of Subjectivity Versus Objectivity

A major issue in all quality of life research is subjectivity versus objectivity - should quality of life components be subjectively chosen by the population under consideration, as their 'felt needs' (Bradshaw, 1972) or should they be objectively selected by others? Further to this a
decision has to be made as to whether the indicator should be subjectively or objectively measured. Thus, at one extreme quality of life indicators may be subjectively chosen and measured, and at the other, choice and measure may be entirely objective. When this latter situation exists then objective measures of the objective conditions of life act as surrogates for their subjective experience (Campbell, 1976). Here lie many potential pitfalls as far as validity is concerned. Objectively chosen concepts may not be the choice of the group to which they are meant to apply: and when these are translated into measurable indicators those chosen may not be the ones that individuals or groups would have selected. For example, a 'respectable' funeral might not necessarily be chosen as a symbol of social esteem as it was by Mrs Jones who stimulated this research. Lastly, if indicators are to be measured objectively they may reflect the values of the objective observer rather than those of the subject. Thus, a quality of life measure may end by being several steps removed from one that would be appropriate to an individual. Rodgers and Converse (1975) state:

'For any measure to be considered a true indicator of quality of life there must be a clear linkage between the measure and the feelings of the people to whom it is relevant'. (P. 127)

The trend in much quality of life research therefore has been to include some element of subjectivity, for increasingly it is recognised that it is difficult, except in very broad categories, to determine what matters to someone else's sense of satisfaction or well-being and even more difficult to measure that satisfaction. This is particularly true in medical
research when the healthy may be attempting to describe and measure what matters to the sick. Presant (1984) conducted research with a sample that included 130 cancer patients, and found that there was a poor correlation between patients and physicians scores, on quality of life, using more than one type of measure. He stated:

'We were surprised to find that physicians were relatively incapable of adequately describing patient quality of life.' (P. 572)

Presant therefore concluded that there was a need for the patient to play a major role in quality of life assessment. Poor correlation between objective and subjective scoring has been found in other studies (e.g. Fayers and Jones, 1983; Najman and Levine, 1981; Zautra and Hempel, 1984). Part of the reason for this situation is failure to understand what is important to patients. As Schmale (1983) states:

'The sense of well-being is a subjective private experience and its determinants are highly personal'. (P. 167)

Najman and Levine (1981) list four principal weaknesses of objective indicators that have restricted the use of quality of life measures in health care - there is disagreement in determining the basic dimensions as to what constitutes high or low quality of life, disagreements about which indicators are relevant, little or no concern to relate inputs to outcomes, and no understanding between the objective conditions of life and the subjective perception of these conditions.
There have also been ethical objections to objective indicators on the grounds that they impose the way of life and motivation of others on patients (Coodley, 1976). Kagan (1983) stated:

"The quality of life is a judgment made by the patient. It is the physician who intrudes with this judgment with pre-conceived ideas as to what is best for the patient". (P. 118)

However, doubt is also expressed about the validity of subjective measures, based on samples that may not be representative of the patient population, and on qualitative data which is subject to different interpretations (Zautra and Goodhart, 1979). Moreover there are some patients for whom it is considered that objective indicators would be particularly appropriate, those with very low expectations, those mentally disturbed and those, such as the very young, who are unable to contribute at all to a quality of life evaluation (Holmes, 1989). Consequently many researchers seek to combine subjectivity with objectivity in their measurements.

It is perhaps difficult to draw an arbitrary line between indicators based on the opinions of patients and those based on those of the professional, for many studies with apparently objectively defined indices are based on a body of knowledge of patients' concerns that have been built up in close contact with patients in clinical practice. However very few overtly describe preliminary research with patients to elicit their ideas as to what the indicators should be, and even those who do may include only a relatively few patients in their founding sample. For example, Spitzer
undertook detailed preliminary work but this was with a sample of 129 in which 84% were healthy persons including some professionals and relatives of patients: none of the remaining 16% of patients were terminally ill. Recent studies have found poor correlations between clinician and patient rated versions on the Spitzer Index (Maguire, 1989).

Schipper, (1984) designed a questionnaire for use with cancer patients, based upon an eleven member panel including patients, spouses of patients, physicians, nurses and a clergyman. However its scores were found to be difficult to interpret and, although it was easy to use it was considered that there were insufficient items on each dimension to measure significant changes over time, moreover few physical symptoms were included. These would have been important in patients with advancing disease. It was therefore not recommended by the the Medical Research Council working party (Maguire, 1989)

One particular time when choice and values may change is at the end of life (Krant, 1974). For the dying patient, there may be a new appreciation of what has been previously taken for granted. There may be a focus on little things, or a major attempt to achieve some old or newly realised ambition in the time that is left (Okazaki, 1983). New factors may surface in consciousness, for example, assurance that death is likely to be peaceful may become a pressing quality of life component (Carey, 1975). Two patients express the change of view that the knowledge of possible impending death brought to them:
'It isn't the most expected things that turn out to be the most precious when one faces possible death. In the dead of winter I longed to see the spring flowers ... I wondered if I'd feel the sun and see the unfolding of the new leaves. Suddenly my job which I took for granted, and often felt fed up with, was desirable, the most important thing in my life'. (Kathleen W, 1979:32)

'Cancer makes people start thinking about the quality of their lives. Everything they do has a keener edge, and they get more out of life ... I am much more aware of the values of each day and the importance of making good use of it'. (David Watson, 1984:161)

Weisman (1972) states an 'appropriate death' is one in which dying is compatible with the ego ideal of the individual concerned. Whilst there is much clinical experience as to the things that matter to patients, and qualitative research such as that of Kubler-Ross (1970) which explores the concerns of dying people, there is little research that has been based directly on asking a sample of dying patients what is important to their quality of life, and in exploring how these factors are symbolised in small ways.

Defining and Applying Quality of Life measures
In describing methods of creating a list of quality of life factors for inclusion in a measuring instrument Dalkey (1972) identified two early approaches, the first was heavily objective, and rather derogatively called the 'armchair approach', it consisted of:
'devising a list of general factors presumed to be significant in determining the well-being of humans ... distilled from clinical lore, sociological think pieces, some psychological and social psychological experimentation and the like'. (P. 86)

These lists of factors were then tested with various groups of people and the conclusion at that time was that armchair lists were probably only suggestive of quality of life. Another method was that of 'public survey' - devising categories directly from samples before introducing them into some form of measurement. Dalkey (1972) states that such surveys in general had their acknowledged weaknesses - difficulty in checking reliability of verbal reports, and 'very little in the way of a conceptual framework to suggest hypotheses and structure results' (P. 91). However they provided some new and useful information such as the finding that the sequence of experiences comprising life do not blend in evaluation into emotional grey but contribute distinctly to quality of life. Thus the survey, starting from the base line of the group to be explored, was able to break new ground in knowledge. It cannot be said that there is such a stark dichotomy of approach today for both methods are often combined in projects, moreover the once somewhat haphazard armchair approach, now consists of using instruments, and whole batteries of measures, specifically developed for quality of life research; the armchair of the present has grown larger and more specific.

Fundamental to attaining the things that make for happiness or satisfaction is the possession of the resources that make them available. One of the most basic of resources is the ability to function
independently, to seek to fulfil one's own needs in one's own way. Given the importance of functional independence it is not surprising that the Karnofsky Index (Karnofsky, 1948), has continued to be used, at least in part, as a measure of well-being for the sick. This single indicator measuring instrument was developed within the setting of palliative care of the cancer patient, as a means of assessing treatment and dependency needs, and focuses on the one dimension, of activity, objectively defined as 'performance status'. The scores range from 100 when there is full independence to 70 when the patient is unable to work and needs care for most personal needs, to 10 when moribund, and 0 when dead.

However, this focus on broad activity alone takes no account of the patient's attitude to the situation, or to aspects of less active enjoyment such as the ability to observe nature through a window, or to listen to music, which may bring great and continuing satisfaction. For this reason the Karnofsky Index is often used today in conjunction with a range of other measures, as in the recent large scale study of terminally ill patients in the USA (Morris, 1986).

In recent years attempts to measure the quality of life of patients have increasingly taken a more global approach that has paralleled the trend to consider psycho-social aspects in patient care. Fallowfield (1990) suggests that there are four essential domains - the psychological, social, occupational and physical. Broad categories of quality of life factor are likely to include levels of ability to work, to undertake physical activity, as well as levels of symptom control, social support, and measures of the patient's emotional response to the illness
A major problem in devising quality of life indicators is the very global nature of the endeavour. Since life is so multi-faceted the list of quality of life factors could become endless and still not be anywhere near complete. In attempting to be as comprehensive as possible some researchers have produced long lists of over 100 items to be evaluated (e.g. Bergner, 1981; Schag, 1983). These have been found to be useful to staff in isolating problems likely to diminish the patient's quality of life, but were not directed specifically to dying patients. If they had been it is doubtful whether patients would have had the energy to cope.

The Spitzer quality of life index (Spitzer, 1981) is an example of a simple broad category instrument that was recommended for use with the terminally ill along with other types of patient. It isolated five main aspects of the patient's life - work, independence in the tasks of daily living, feelings of wellness or illness, social support, and mental outlook, which were related to the week previous to the time of assessment. However, Spitzer cast some doubts as to its sensitivity with the dying:

'We cannot discount the possibility that the QL-Index has unrecognised defects which make it somewhat insensitive at the extremes of possible scores. On the other hand we may be underestimating the ability of the human mind and spirit to compensate for major infirmity'. (P. 596)
I tried the Spitzer Index and found that dying patients tend to find compensation in aspects of life that are not featured overtly in the measure, or in the minds of those objectively completing it: for many of those who stated that they were experiencing at least a certain degree of satisfaction or happiness with life achieved an extremely low score on this scale. Spitzer (1987), has since suggested that a broader interpretation of quality of life would be more appropriate. The apparent lack of sensitivity may also have been due to the constraints imposed by the effort to produce a scoring system based on aggregation. Each section had a top possibility of two marks, and thus the total quality of life score was out of ten. Who is to say that for any one person a top score in any category is equal to 20% satisfaction with life, that one category would score the same total as another, and that even if this were so for one person it would also be so for another. Aggregated scoring systems are fraught with difficulties, which some consider to be likely to be insuperable (Clark and Fallowfield, 1986).

It is not surprising that the production of valid global scales is so difficult, for this implies reducing human individuality and experience to bounds likely to be almost beyond reality. Recent reviews in Britain and Australia of possible instruments for use with cancer patients come to the conclusion, that none meet all the criteria of validity, reliability and useability (Donovan, 1989; Maguire and Selby, 1989). Maguire and Selby state:
'A multi-dimensional scale which is specific to patients with cancer, meets all the assessment criteria and provides scores which have relevance to clinical judgement remains to be developed.' (P. 440)

The Medical Research Council Committee recommended 'as best bet' a scale specifically tailored to symptoms, suggesting that work with certain problems or with specific groups has the most potential to contributing to the whole at present. Both of these reviews make the same recommendation; that development of global scales would require further enquiry into the factors that were important to the quality of life of patients. For as Donovan (1989) stated:

'Review of the literature reveals relatively few attempts to define the important domains of life for cancer patients' (P. 960).

Maguire and Selby (1989) see this best attained through use of in-depth interviews with cancer patients to determine which concerns are important to them, followed by the development of a questionnaire rated by patients, and then validation of this questionnaire over time against independent in-depth assessments by trained interviewers. These reports indicate therefore that insufficient is known of what is important to cancer patients and that this knowledge should be sought to provide a foundation for future work. It is hoped that this thesis may go some way in providing some answers to the need to know more about the domains that are important to the quality of life of dying patients.
Quality of Life Components in Serious Illness

Since quality of life is so multi-dimensional in nature many factors contribute to the sense of happiness or well-being. Donovan (1989) in common with others, sees an adequate conceptualisation as including physical, psychological, social and spiritual domains. Such an understanding is consistent with the experience gained with dying patients over the years. However, it is virtually impossible to compare one research project with another because of the variety of ways in which the variables under consideration are defined and the wide variety of measures employed. For example the association of symptom distress with quality of life has been investigated using a short list of five symptoms with a mixed sample of healthy people, cancer patients and diabetics, and measured by Linear Analogue Scale (Presant, 1984); it has also been investigated with a list of ten symptoms and measured by Likert type scale with a small group of cancer patient, some of whom had a poor prognosis (Young and Longman, 1983). Moreover physical distress may have a meaning over and above the immediate experience of discomfort. Priestman (1984) observed that even quite severe side-effects of cytotoxic therapy could be tolerated as long as the treatment was producing hope of remission or cure.

Carey (1975) found that fear of painful death was one of the chief concerns of those who were dying. The importance of symptom distress in studies indicates the relevance of physical comfort to quality of life.
Poor health also has an impact on ability to function, which in turn effects independence and life-style; thus these concepts feature in many studies (e.g. Burge, 1975; Spitzer, 1981; Lewis, 1982; Young and Longman, 1983; McGinnis, 1986). Some studies have found that quality of life was only really diminished when ill health was considerable and seriously effected the ability to function (e.g. Freedman, 1978; Munns, 1980). In the latter study it was found that expectations played a part with elderly people. One of the means whereby change in life-style has been measured has been through time spent in hospital (e.g. Presant, 1984; Lewis, 1982). Young and Longman (1983) found that social dependency was inversely associated with quality of life, and Carey (1975) found that the ability to exert as much control over life as possible and retain as normal a life-style as possible, was an important factor in coping with dying.

The emotional response to serious illness is also viewed as an important variable in quality of life. Many studies measure mood and levels of emotional stress (e.g. Priestman and Baum, 1976; Presant, 1984; Morris, 1986). Others investigate stages of emotional adjustment and the factors that predict such adjustment. Carey (1975) found the variables of adjustment included, level of physical discomfort, previous close contact with a person who was dying, religious orientation, a feeling of great interest and concern on the part of others, and amount of education. It was found that female respondents who had been able, in the past, to discuss death frankly with others who were dying, had much greater ability to cope with their own terminal illness.
Thus knowledge of the situation and coping styles become relevant and coping and awareness of dying becomes another variable of interest in quality of life research (e.g. Wilkes, 1977; Martocchio, 1986; Okazaki, 1983; Morris, 1986). Other variables important to emotional response and to quality of life, feature in studies as general attitudes to life (e.g. Padilla, 1983), and plans or purpose for life (e.g. Lewis, 1982). These include levels of life satisfaction and also feature such factors as fun in life. This vast body of research into just one aspect of quality of life - the emotional - indicates the multitude of inter-related factors that comprise quality of life for seriously ill people.

Social relationships are recognised as important to quality of life, for they are a means of giving and receiving emotional warmth and support. Young and Longman (1983) found that social support systems were often mentioned by respondents and that family relationships were important. Thus relationships are investigated in terms of their quality (e.g. Priestman and Baum, 1976), in terms of self-esteem they provide (e.g. Presant, 1981; Lewis, 1982), as well as in terms of the anxiety that social responsibilities produce for the dying (e.g. Carey, 1975).

However, a review of quality of life literature indicates that most is not very helpful to a micro approach, of defining components within components, for it would seem that the imperative in quality of life research to produce manageable and measurable indicators somewhat constrains researchers to focus on categories that are insufficiently narrow. Moreover the focus on problems, (e.g. Schag, 1983), although broken down into smaller components, may indicate what is likely to need
correction, but will not indicate what is positive in the patient’s situation, in terms of interests and other enjoyment, and in terms of the positive aspects (if any) of the illness experience; for the experience of seeming tragedy can impact life positively as well as negatively (Schmale, 1983; Holmes, 1989). Such knowledge would be useful for in care it is the aim not only to correct the negative but to build on that which also enhances the patient’s quality of life.

Consequently there is little research to more fully inform those who would seek to benefit the patient in the everyday face to face situation, such as in nursing rather than in medical decision making. For example, one might know that in general a sense of self-esteem was important to quality of life but be unaware of the many factors that contribute to this in institutional care. Access to some of the qualitative work behind studies might be very helpful but in most the qualitative data seems to have become swallowed up in the effort to reduce in order to measure.

From the field of gerontology Thomas and Chambers (1989) see the need for a new hermeneutical approach (Ricoeur, 1981) to the study of quality of life; they discuss the limitations of structured measures of subjective well-being, that are based initially on restricting structured questions, and then face the ‘context stripping’ that forms part of the process of data collection and analysis. They consider that:

'Subjective dimensions which touch on the core of a person’s sense of meaning and self-definition, may not be accessible to survey-type, structured questions. (P. 284)
CONCLUSIONS

One conclusion from this review has been that more needs to be known about the factors that matter to the quality of life of patients dying of cancer, and of how they change over time. It is important to discover those factors that enhance as well as those that diminish quality of life - to focus on problems is not enough; and to discover the smaller symbolic components of these factors. It has been suggested that such enquiry requires in-depth interviews with patients as most appropriate to eliciting subjective meaning (Ricoeur, 1981; Maguire and Selby, 1989). However, the subjective approach has been criticised in that the statements elicited may not be representative of the patient population, and there may be difficulty in checking verbal responses (Dalkey, 1972; Zautra and Goodhart, 1979).

It is hoped that this research may contribute in some way to the need for more information of the domains that are important to the quality of life of dying patients, for its primary aim is to identify as many quality of life factors as possible from in-depth interviews with terminally ill patients; and whenever possible to conduct more than one interview with patients in order to provide some insight into change over time. It is also hoped that this project will go some way to meeting the criticisms of qualitative and subjective research, in that the response is obtained from two samples, one of them 'random' in two completely different settings - a hospice and the acute wards of a large general hospital; and the actual statements made have been placed within the context that they were made, thus providing the reader with some opportunity of checking the findings. These issues are discussed in chapter 5.
Another conclusion arising from the discussion in this chapter is that the context within which quality of life is made - of expectation, reference group and priority - is central to the understanding not only of what is important, but why it is important. It was considered likely that the quality of life question in this study would elicit a background of reference groups, expectations and priorities therefore the second aim of this project is to explore the context in which quality of life factors are presented as important to the understanding of quality of life.

The third aim of this research is application of the findings to clinical care, to which the first two aims make an essential contribution. It is hoped that the findings will be useful in the day to day care of patients, whether or not they might be translated into measurable indicators at some future time. An issue that has arisen in this chapter, of relevance to clinical care, is the social context within which needs are met, for there often have to be trade-offs in health care. One form of trade-off is the outcome of the bargaining between the sick and helpless and the society upon which they must lean to meet their needs. Mor and Guadagnoli (1988) say of a recent attempt in the United States to examine and compare selected quality of life instruments used in health care (van Knippenberg (1988):

'Much more basic measurement work is required that contrasts the personal vs the societal definitions of quality of life and their associated values'. (P. 1057)
Mor and Guadagnoli (1988) suggest that it is especially important to attend to the meaningfulness of items, and focus on a consensus between patients and non patients as to what constitutes quality of life. As noted earlier in this chapter there is a need to find new bargain patterns between the sick and society (Levine and Kosloff, 1978). If the aim in terminal care is quality of life for the patient then these new bargain patterns have to be discovered within this dimension. It is hoped that respondents, talking about quality of life within the context of care, will be able to indicate the source of their quality of life, whether as discussed in Section I, this stems from the organisation, the expertise, or the spirit or interactions of care, and in so doing shed some light on the kind of bargain they would best like struck.
SECTION III

METHODOLOGY
CHAPTER 5 - ACCESS, ETHICS AND CHOICE OF METHOD

This section discusses the many issues involved in undertaking this project; as has been stated in the introduction, the project was initially undertaken at St Joseph's Hospice, whose history and aims have been discussed in Section I. It was later replicated in part in the acute wards of a large District Hospital on the South coast.

Having decided that the primary aim of the research was to ask patients in the last stages of disease what mattered to their quality of life, not the least of the issues was: could and should this question be asked of people who were so severely ill; would it be possible to gain access to them for this purpose; and if so, would the research be likely to harm them in any way? Having addressed these questions the focus could be turned to the various stages of research; how was this question to be asked in terms of choice of research instrument and type of sample, and how was the resulting data to be analysed?

GAINING ACCESS

Access to a sample of dying patients at St Joseph’s Hospice was potentially open to me as I was already a member of staff there. St Joseph’s is one of the largest hospices having 55 of its 110 beds set aside for patients designated as in a terminal stage of cancer. Patients are admitted to these beds when it is considered that they are in need of palliative care, and that treatment aimed at remission or cure is no longer feasible. Moreover admission criteria indicate that it is thought
likely that patients have weeks or months to live rather than a longer period.

At the time that this project was being considered in 1983 I was engaged in other research there and so was already viewed as a researcher with access to the wards for this type of purpose. Moreover while engaged in assisting in a variety of research projects I was beginning to gain experience in talking with dying patients, and it was during this time that the idea lying dormant from the meeting with Mrs Jones (Introduction) came to fruition. Most important, in an institution that was very protective of its patients, and diffident about research, this type of interaction was proving to be acceptable to the patients and ward staff alike.

While the project was discussed briefly at a small informal 'in-house' committee of Sisters and Medical Staff, the real basis of the permission for research rested upon the trust gained by the senior staff of St Joseph's. As was stated by the Sister Superior, 'I hate the idea of research - don't talk to me about it, but you can do it because we trust you.' Although this was perhaps pleasing to hear it provided a most uneasy structure upon which to rest and there was always the fear that a misunderstanding by a patient of what had been said would result in immediate withdrawal of permission, as had happened once before in research instituted by someone else. However there was always a welcome in the wards and willing assistance given there.
Permission to research in the District Hospital had to be slowly negotiated through a series of committees, facilitated by the District Patient Care Adviser who had first been approached. The knowledge of having overcome this series of hurdles gave a greater feeling of confidence but although access was granted in principle there was no automatic right to enter wards. I found that ward sisters had a similar, and welcome, protective feeling towards their patients as the hospice; and access had to be negotiated with each one, who needed to be reassured that the research was unlikely to do harm. On some occasions a sister would hover out of earshot, but in the background, to note whether a patient was becoming distressed. As the ward sisters relaxed and became more assured they became more willing to inform me when they had suitable respondents; and so the research was able to proceed.

ETHICS
Ethics are important in all research but never more so than when the potential respondent is severely ill and relatively helpless. Many dying patients may feel too ill or weary to be involved, but depending, as they so heavily do, on the institution, feel some sort of obligation to cooperate. They may also fear being critical of the staff. Moreover the little energy that is available to them after the struggle of daily existence might be better employed in their own chosen activities, such as relating to family and friends, than responding to the research. They too, like other respondents may wonder why they particularly have been chosen, and perhaps, because of their situation, imagine that it has some extra fearful explanation. Quality of life research should hardly be there to diminish the quality of life of its respondents. However,
research with dying people, such as that by Hinton (1972), Feigenberg (1980), and Kubler-Ross (1970), indicates that given appropriate conditions and safeguards, patients often welcome the opportunity to talk and to express their feelings, and benefit from so doing.

Another issue that needed to be considered in asking these patients to talk about quality of life was what distressing thoughts were likely to emerge, with which the patient would afterwards be left to cope. Would one be like the proverbial ‘bull in a china shop’ and leave a trail of destruction behind? An incident occurred in the preparatory stage which highlighted the seriousness of such an undertaking. A patient was asked what mattered to her quality of life and a long conversation ensued. It ended in an extensive life-review in which the patient reviewed major events and concluded that they had been resolved satisfactorily. Finally she discussed the sense of satisfaction that she had in that everything was sorted out and she had given instructions as to her funeral. A few hours later she died very peacefully but somewhat unexpectedly. Although it can never be known with any certainty it was felt that the working through to satisfaction in this life review might well have helped her to peacefully relinquish her hold on life, but of course there might be other consequences if life review had ended with a less satisfying conclusion. At this point the advice of the psychiatric advisor to the hospice, a very experienced researcher in this field, was sought. I am most grateful to Dr Parkes for his advice and for his encouragement to press on. The context of the research was planned to attempt to take into account the potential hazards that could be envisaged.
Patients were not approached until they had had at least three days to settle in the ward. Prior to this a senior member of the ward staff was asked if the patient was fit to be interviewed; only when the answer was in the affirmative was the patient invited to take part. If, as the interview preceded, the patient appeared to tire, then a suggestion was made that the interview be terminated and an opportunity be given for completion after a sleep. Another reason for automatic termination was the arrival of visitors.

Ethical considerations require that the research be clearly explained to potential respondents so that consent may be given on an informed and non-pressurised basis. The patient was first greeted by name. I then introduced myself as a nurse researcher, and in the hospice, a member of the teaching staff. At this point it was found helpful to orientate the patient, giving time for the situation to be gently assimilated. In the hospice the direction of the teaching unit was pointed out through the windows and it was explained that we had many doctors and nurses as visitors there; and that they wished to learn with us more of how to help their patients to experience the best possible quality of life whilst in their care. The hospital patients were just told of the need to learn more. It was then explained that in order to achieve this it was necessary to ask patients what was important to their quality of life, that is, to answer the question, ‘What is important to your quality of life today?’

It was further stated that of course quality of life was a very individual thing and what mattered to one person might not matter to
another in the next bed (usually met with a nod of agreement from the patient). It was then explained that this was why it was important to ask as many people as possible, and as it was not possible to ask everyone, a method had been chosen to select people by chance, according to when they were admitted, who might be available, and when there was the time to interview.

Patients were then told that if they did decide to take part their comments would be used for general teaching purposes but what they said would never be linked with them as persons, so that they could be identified. Ward staff would not be told anything of what had been said or whether they had agreed to take part or not. They were also promised that should they prefer not to take part this would make no difference to their care or treatment. This invitation to decline was then informally reinforced, "If you feel you would rather not take part just you tell me to buzz off right now and that will be quite alright and you won’t be approached again".

At the end of the interview each respondent was thanked for their valuable contribution to the research and to teaching. If the main, or last comments had been negative then further time was spent in general conversation with an effort made to concentrate on something pleasant. If there was distress, a suggestion was made that the patient shared this with a member of the ward staff; the researcher acting as a bridge if this seemed to be required, but only with the patient’s permission.
CHOICE OF METHOD

A further consideration was choosing a method that would be appropriate to the aims of research, and that would be likely to maximise the potential of responses. Since the literature search had identified gaps in knowledge of the factors that made for quality of life of dying patients, a questionnaire with pre-determined categories would be of little assistance. An interview comprised of open-ended questions would be more suitable for eliciting patient's feelings and experiences. Madge (1965) states of the interview:

'The principal application of the interview in social science is its use for the purpose of making people talk about themselves'. (P. 150)

Another point in favour of the interview was that it had been found useful and fruitful for others researching with dying patients (e.g. Hinton, 1963; Kubler-Ross, 1970; Qvarnstrom, 1978). Moreover the interview was consistent with the type of qualitative methodology associated with symbolic interactionism, which seeks to understand social meanings in terms of symbols (Blumer, 1962). It would therefore be useful in identifying such phenomena.

Interviews may be classified according to how structured they are. At one end of a continuum all questions are precisely structured in advance; this would have the disadvantage of imposing a form upon the response without having the basis so to do. At the other end of the continuum the interview may be completely unstructured, corresponding to everyday conversation. Unstructured interviews are particularly useful in the
exploratory stages of research when little is known of a subject and when depth of understanding is more important than large scale coverage (Stacey, 1969). This would be appropriate in that few prior assumptions would be required but there was the danger that conversation would stray from the topic, taking time and effort, perhaps not easily available to the patient, and becoming unmanageable to record and analyse. In this case less would be gained than through the use of a framework that was slightly more formal.

The focused interview (Merton and Kendall, 1956) provided a compromise. It is particularly useful where experiences, feelings, reasons and motives are concerned and allows for these to be expressed, but at the same time permits the interviewer to make use of probes. Moreover response to open ended questions would allow a background of expectations and reference groups to emerge, at least to the degree that they do in normal conversations. Well organised interview schedules are thought to produce high response rates (Shipman, 1972). In this project there was but one main question around the quality of life concept, since this concept has been found as best left undivided in research (Szalai, 1980), but probes would be an important aid in eliciting material that would illuminate answers. In addition some supplementary background questions needed to be asked and, as will be discussed, it was important that they were asked in the right order. The interview schedule would assist here. The interview is among the more time consuming methods of research for a mass of data has to be sorted and analysed but it has the advantage that the interviewer is able to observe responses and reassure respondents.
Validity
The research method has not only to be appropriate to the aims of research it also has to be capable of eliciting data that corresponds to the concepts under investigation; it has to have validity (Manis, 1976). As discussed in chapter 4 the concept quality of life has been shown over several years to have the potential of eliciting valid response, for it is readily and consistently understood by people. It was planned to use the occasional comment, "So this is what matters to your quality of life!" to affirm that the interview was being kept within conceptual bounds. Validity is at risk when the respondent has reason to resent the interviewer, or fear giving a truthful response. Care was taken to emphasise the interview as one in which the interviewer was receiving from the patient, and the patient's advice was sought as to where the interviewer should be seated so that there was no invasion of personal space. The open-endedness of the question meant that patients only discussed what they wished to discuss, and it was hoped that the framework of confidentiality might prevent failure to disclose information for fear of causing offence to staff.

Triangulation
'Triangulation' (Denzin, 1970) was also used to provide a check on the validity of the data. This is a method whereby the research situation is looked at from a number of perspectives; should these clash in their evidence then there is cause to question validity. One means used was that, whenever possible, the mind of respondents was re-focused on the quality of life concept by asking them to complete a quality of life visual analogue scale at the end of the interview.
FEELINGS ABOUT QUALITY OF LIFE AT PRESENT

Delighted________________________________________________________________________Terrible

10 cm

They were then asked to say what they were thinking about as they did so. Visual analogue scales have been used for some years in the study of quality of life and shown to be useful and valid (e.g. Priestman and Baum, 1976; Fayers and Jones, 1983; Presant, 1984; Clark and Fallowfield, 1986). In discussing methods of measuring quality of life Clark and Fallowfield (1986) state:

'Visual analogue scales (VAS) ... provide a much more satisfactory method of measuring quality of life. These tests employ lines the length of which are taken to denote the continuum of some emotional or physical experience such as pain or anxiety. The line in any VAS is usually 10 cm long ... the patient is instructed to mark along the line a point that corresponds to his or her perception of the experience'.

(P. 1)

The most usual response to this question as to what thoughts accompanied the completing of the VAS was, "What I have just been talking to you about." This provided some assurance of validity.

Another method of assessing validity was to look for consistency within each interview and another to undertake a brief interview with a senior member of staff who knew the patient, asking what they thought seemed important to that patient's quality of life. Many of these staff were particularly sensitive to patients' needs. Whilst it could not
necessarily be expected that they would have extensive knowledge any major discrepancy could be noted.

Finally there was also the opportunity on some occasions to gain information from the participant observation that was associated with the ward contacts that were part of my job at the hospice - this included sometimes being able to attend the multi-disciplinary meetings on each ward when each patient was discussed in some detail. All these sources of information were used as a check upon validity, and have been used in this thesis.

Reliability
The reliability of the research was another key issue to be addressed. It centres around the question; if the investigation had been carried out at the same time, and in the same conditions, by someone else using the same methods, would the results have been the same? Interviews are never completely reliable (Shipman, 1972), for the influence of the interviewer enters in as a source of bias; interviews are forms of social interaction with all the subtle verbal and non-verbal behaviours that influence response and counter-response. Moreover, in a personal interview, when probes are at the discretion of the interviewer then someone else might probe in a different way. It is hardly possible that one interviewer would obtain identical data to that of another. However the situation can be controlled in part by strict adherence to a set of rules as to this interaction, to how the main question is to be put, to the type of probes allowed, and to the general demeanour of the interviewer.
After as uniform as possible an introduction to the research the question - "What is important to your quality of life today?" - was put to the respondent as it stood with no suggestion as to what this might cover. The probes depended upon the assumptions that lay behind the research. These were very simple; that people had psycho-social as well as physical needs. Therefore, the only extra directional probing allowed was when at an apparent end to an interview the respondent was noted to have focused on matters that were exclusively physical or exclusively psycho-social. In the former case the probe was, "Up until now you have been telling me what is important to your quality of life as regards your body, is there anything else that is important, to your mind perhaps?" In the latter case, mind and body were reversed. No other probes were used except one that asked for further explanation; "Could you explain a bit more about this please?" An effort was made to show interest by listening intently and writing everything down, but at the same time it was endeavoured not to elicit specific responses through facial expression. At the end of the interview respondents were asked "How comfortable are you". (The interview schedule will be found in Appendix 2, and the staff questionnaire in Appendix 3).

A tape recorder was considered as a means of data collection, and this has been successfully used by others (e.g. Qvarnström, 1978), but such was the general diffidence about any research in the hospice I felt this might be viewed as too intrusive. Therefore interviews were recorded by hand using a 'home-made' form of shorthand, so that everything that was said could be collected. This was not too difficult since the weakness of many of the respondents meant that they were only able to speak fairly
slowly and for a comparatively short period of time, ranging from about ten to twenty minutes.

PREPARATION FOR RESEARCH

Before embarking on a main study, pre-tests and a pilot study will indicate whether people are likely to co-operate, whether the sampling frame and the research instrument are adequate (Krausz and Miller 1974). I was fortunate in being in a fairly unusual situation in which I had access to persons similar to potential respondents for many months before the research was begun. Therefore, preparation focused largely on pre-tests consisting of many conversations initiated around what mattered to these terminally ill patients. These indicated that people were willing to talk about what was important to them, and moreover that they appeared to enjoy doing so.

These conversations were followed up, when general research permission had been obtained, by a small series of more formal interviews (n = 5), in which methods of recording were tested and experiment made with various forms of probe. These indicated the necessity of restricting probes to the bare essentials if the direction of the interview was not to be influenced. Throughout these stages it was noted that nearly all patients understood quality of life in global terms. The extreme weakness of many patients and their rapidly changing situation was noted; it seemed essential that they should only be asked to concentrate upon what was important to the quality of life of that day. These months of preparatory work also provided an opportunity to generally explain the aims of the research, test the reactions of staff to the idea, and work
out how a sample might be obtained whose choice was not biased by self or others.

THE SAMPLES

As discussed in the chapter 4, the aim of the research was to identify quality of life factors chosen by dying people. The concept of dying needed some consideration, for a dying trajectory may be long or very short, the patient may be labelled as 'dying' but be unaware of the situation, or have a full understanding which others around are willing to share. Between these extremes there may be many different positions on this continuum (Glaser and Strauss, 1965). As discussed in chapter 4 people may experience a change of values when they knowingly face dying. However, knowledge that the patient has been told of a poor prognosis is no indication of their acceptance or acknowledgement of the fact at any one time; for some people will on one occasion appear to acknowledge their condition and at other times deny it (Weisman, 1972). One is not to know before an interview what the prevailing response will be. The sample therefore was likely to encompass those unaware of their situation and those consciously or unconsciously seeking to deny it, as well as those openly accepting. It was hoped that if the patient’s current expectations about their prognosis arose at interview then their influence, if any, might be noted with those of other expectations.

The Definition of 'Dying'

The feasible definition therefore for the purpose of selecting a sample of dying persons was an objective administrative one, centring on those whose stage of illness was such that they needed to be in receipt of
palliative care. Calman (1983) proposed a definition of terminal illness that was appropriate to these patients:

'Terminal illness in cancer patients occurs when such patients have been accurately diagnosed, in whom death does not seem too far off, and in whom medical effort has turned from the curative to the palliative'. (P. 2)

The Hospice 'Random' Sample

Selection of patients from the hospice was relatively easy for it used similar criteria to the definition above for admission to its 55 beds for patients in an advanced state of cancer. Table 5.1 indicates the bed occupancy situation over the years that the research took place. There was very little difference between the two reports examined:

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beds available</td>
<td>25.0</td>
<td>30.0</td>
<td>55.0</td>
</tr>
<tr>
<td>Patients treated</td>
<td>303.0</td>
<td>330.0</td>
<td>633.0</td>
</tr>
<tr>
<td>Number of deaths</td>
<td>292.0</td>
<td>315.0</td>
<td>607.0</td>
</tr>
<tr>
<td>Av. length of stay in days</td>
<td>20.5</td>
<td>26.5</td>
<td>23.5</td>
</tr>
<tr>
<td>% Patients discharged</td>
<td>3.5</td>
<td>4.5</td>
<td>4.0</td>
</tr>
<tr>
<td>% Patients died in hospice</td>
<td>96.5</td>
<td>95.5</td>
<td>96.0</td>
</tr>
</tbody>
</table>

* St Joseph’s Hospice Annual Report - 1st April 1984 to 31st March 1985
St Joseph’s Hospice Annual Report - 1st April 1985 to 31st March 1986
The sample from St Josephs' was therefore drawn from a population of patients who had an average life expectancy of three to four weeks at admission; this ranged from a few hours to several months. Of those who were discharged the occasional patient experienced some form of lengthy remission of their illness, others died at home or were readmitted to the hospice to die there.

Experience in the pre-test period had suggested that although a random sample is not particularly consistent with qualitative methods, it would be better to try to introduce some element of randomness in the design; if one was not to end up with all the patients who felt happy and wanted to talk, or those who were miserable and needed to unburden their feelings. A random sample has been defined by Moser and Kalton (1971) as one in which:

' Each possible sample of n units from a population of N units has an equal chance of being selected ' (P. 63)

Since research could only be gradually undertaken as the researcher had time, and the patients' situation was changing so rapidly, an initial list of patients would have been useless for many would have died before being able to be interviewed. It was therefore decided that selection should be made from the admission book, and be on a continuing basis. When time was available the book was consulted and patients selected who had been admitted three days previously. If there were none, or these were insufficient for the time available, then the fourth day back was consulted, and so on. This method can only be related to the principles
of randomness in that at this stage it avoided the bias of choice by
staff or researcher. In the event each 'unit' did not have an equal
chance of final selection for on approach to the wards it was found that
many patients had already died and others were too ill to be interviewed.
One hundred and sixty seven patients were first selected in order to
achieve a sample of 52. (Table 5.2):

| Table 5.2 Hospice patients initially selected for 'random' sample - non response |
|-----------------------------------|-----|-----|
| Had already died                  | 57  | 34.0|
| Too ill/confused                  | 45  | 27.0|
| Unable to communicate easily*     | 13  | 7.5 |
| Declined to take part             | 1   | 0.5 |
| Sample                            | 52  | 31.0|
| Total                             | 167 | 100.0|

* Patients unable to communicate easily were those who were
defead, aphasic, or had a very poor grasp of English

The characteristics of the sample that emerged have some overall
similarity to that of the population from which they were taken, Tables
5.3 and 5.4. However, for the reasons stated it under-represented those
who were most ill.

<table>
<thead>
<tr>
<th>Table 5.3 Characteristics of hospice 'random' sample and hospice population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample n=52 Hospice n=633</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Admitted from home</td>
</tr>
<tr>
<td>Age (Mean)</td>
</tr>
</tbody>
</table>
Table 5.4 Primary site of the most common cancers - hospice ‘random’ sample and hospice population

<table>
<thead>
<tr>
<th></th>
<th>Sample n=52</th>
<th>Hospice n=633</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung</td>
<td>25%</td>
<td>25%</td>
</tr>
<tr>
<td>Breast</td>
<td>19%</td>
<td>11%</td>
</tr>
<tr>
<td>Colon</td>
<td>10%</td>
<td>7%</td>
</tr>
<tr>
<td>Stomach</td>
<td>8%</td>
<td>9%</td>
</tr>
<tr>
<td>Prostate</td>
<td>8%</td>
<td>7%</td>
</tr>
<tr>
<td>Other</td>
<td>30%</td>
<td>41%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100%</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

The Hospice Convenience Sample

The conviction that some element of randomness should be introduced at the initial stage proved appropriate, for once the research got under way ward staff came to feel that patients often benefited from their inclusion in it. There then followed requests for others to take part, for reasons that they ‘needed’ to talk, or were particularly articulate. Thirteen patients came to form a separate, and unexpected convenience sample (Table 5.5). This data has its own identification in the analysis - alphabetical lettering followed by the letter D (e.g. Mrs AD). While the comments of these respondents have been used to illuminate concepts, they have not been included with other statistics.

The Hospital Convenience Sample

The Health Authority from where the third sample was obtained, in order to determine whether the same quality of life factors would be selected by patients in a hospital as in the hospice, was first approached because it was within reasonable distance of my home by car or train. Being on the South Coast it was also felt that it would provide some contrast to London. After some discussion and enquiry the research was welcomed there and approved by a series of committees.
This Health Authority has a large and innovative school of nursing, whose students move between several hospitals in the City. The hospital where the research took place was a general hospital with many acute wards for medicine and surgery. These were in older type buildings, many of the wards being of Nightingale style.

Due to the different conditions in the hospital obtaining the selection of the sample there had to be on a different basis from the quasi-random one of the hospice. There was no list to consult of patients diagnosed as 'terminally ill', and such patients as fitted this category were scattered throughout the acute medical and surgical wards. The approach was therefore to contact each ward over a period of three to four weeks and ask if they had a patient who fitted this description of terminally ill, and if so, whether it would be possible to interview them. Twelve acute medical and surgical wards were contacted and patients came from ten. A sample of 22 respondents was obtained within the time available. There were no refusals (Table 5.5):

<table>
<thead>
<tr>
<th></th>
<th>M</th>
<th>F</th>
<th>Age Range</th>
<th>Av. Age</th>
<th>Sample size</th>
<th>Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice 'Random'</td>
<td>22</td>
<td>30</td>
<td>44 - 86</td>
<td>69</td>
<td>52</td>
<td>74</td>
</tr>
<tr>
<td>Hospice Convenience</td>
<td>4</td>
<td>9</td>
<td>42 - 86</td>
<td>65</td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td>Hospital Convenience</td>
<td>7</td>
<td>15</td>
<td>44 - 81</td>
<td>69</td>
<td>22</td>
<td>23</td>
</tr>
</tbody>
</table>

THE TIME SPAN OF RESEARCH

The first interviews in the main research at St Josephs' Hospice began around the beginning of 1984 and ended at the end of 1986. This is a long period but the research was being conducted alongside a full-time job, plus engagement in related research projects, and family commitments at
the end of each day. Each day included a four hour journey in all, two hours each way between home and hospice.

Another reason for the lengthy research period was that it was surprising how very difficult it was to get over to the wards at an appropriate time to interview. Most of the morning was not good as nursing care or ward rounds were being undertaken; then there was lunch, after which patients were often asleep. There could be visitors throughout the day but mainly they started to arrive in the early afternoon and often stayed until late in the evening. It was important to them to spend as much time as possible with the loved ones they knew they were soon to lose.

The situation was very different in the hospital since the only reason for my presence there was this piece of research. It was however also difficult to find time that did not conflict with other activities. The interviews were conducted on three days a week over a four week period in September 1987.

ANALYSING THE DATA
As in the planning of the earlier stages of research it was important to be aware that distortion could enter into the analysis, for when data is qualitative, bias can be introduced by the selection and interpretation of the researcher. Since many people engage in an area of research because they have a particular interest in it, there is always the danger that the researcher's point of view will intrude, and that data will be
selected that enhances the researcher's own ideas. As Shipman (1972) states:

'An author is a man with normal healthy prejudices, restrained only by the research technique he has used and his ability to suppress his urge to persuade, convert, or impress'. (P. 13)

The more, therefore, that strong feelings are held, the more necessary it is to have means of restraint built into the research. Perhaps the most basic necessity is to be aware of the situation. As regards this project the author had some prejudices, for after many years of nursing in various settings it had come as something of a wonderful discovery that many of the hospice patients could be so alert and appearing to experience some quality of life so near to death; the inference was that this must be due to the hospice and its principles of care. Moreover as a member of the teaching staff at the Hospice, with a real affection for St Joseph's, I was enthusiastically endeavouring to promote these principles, so that they should be adopted elsewhere. In the search for quality of life factors it was easy to hope that the results would justify these ideas and the Hospice itself as an institution. This needed to be thought through and on reflection came the realisation that the commitment that existed was primarily to the improvement of the care of dying people wherever they were; what mattered was that quality of life factors be identified and adapted in different situations, whether or not these advertised the possible benefits of this or any other hospice.
It was important however to try to introduce some restraints into the research technique, to diminish unconscious bias. The first was the attempt to attain a 'random' sample rather than one that could be full of satisfied clients. The second was to seek a further sample to determine what factors made for quality of life in a different, less specialist setting, in which patients with different expectations might be equally satisfied or dissatisfied, for the same or different reasons. Another was to particularly note all those comments that might negate any hidden agenda, around the sanctity of hospices, and to use them. The comments that have been negative about the hospice as well as those that have been positive are reported in this thesis. Lastly it was important to place comment in the context within which it was received; thereby giving readers the maximum opportunity to judge for themselves.

THE FINDINGS - AN INTRODUCTION

The findings are presented in five main themes that respondents have related to their quality of life. These are:

1. Quality of life and having physical comfort - Section IV
2. Quality of life and having emotional comfort - Section V
3. Quality of life and having warm supportive relationships of love and belonging - Section VI
4. Quality of life and having acceptable identity - Section VII
5. Quality of life and having purpose in, and for life - Section VIII
The main concepts of these five themes emerged from the start of the research (Table 5.6), and were consistently presented throughout the project, greater insight being developed as it proceeded. Thus the need for physical comfort appeared as the need that had been experienced for relief from distressing symptoms; for example, pain already being cited by three of the initial subsample of 5. The importance to quality of life of emotional comfort emerged not only in the distress suffered - depression, fear, and anxiety - and the stress of shared care already featuring, but in the attempts to meet this distress by personal efforts of hoping and coping as well as by the gratitude with which emotional comforts in care were received. At this early stage the importance to quality of life of mutual warm supportive relationships had also appeared and there was already indication that the institution could also provide friendship and a sense of belonging. There also emerged from the beginning the importance of the identity of the patient as a unique and social individual and the threat to the sense of identity that the illness situation could pose. Finally the importance of meaning to quality of life had already been presented in terms of religious faith and in life review.

Table 5.6 Quality of life factors offered by the first five respondents of hospice 'random' sample and hospital sample.

<table>
<thead>
<tr>
<th></th>
<th>Hospice n=5</th>
<th>Hospital n=5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical comfort</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Emotional comfort</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Warm supportive relationships</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Acceptable identity</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Purpose in life</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

In addition to these quality of life factors there were major issues associated with all the main themes, and these also appeared at this
time. Issues of choice and control were important to all, the patient being frequently an active partner with care staff rather than a passive recipient. Expectations and reference groups were presented spontaneously by all but one of these early respondents and provided a context within which comments were set. This was an immediate link with theory of needs, substantiated by that which was to follow. There was also already a hint that the factors contributing to quality of life or happiness could remain stable over several interviews, but that the level of the measure of quality of life could fluctuate with the feelings and happenings of the moment. Finally insight was already being gained into factors in care - its organisation, expertise and interaction that contributed to quality of life or its lack.

Thus right from the beginning the pattern of response was taking shape; quality of life was appearing as global rather than restricted in nature, and a basis was being provided for meeting the research aims of identifying quality of life factors and the context in which they were presented, and for identifying response that could be used in clinical application.

The above categories of quality of life factor have a very close resemblance to the concepts of the Maslow Hierarchy of Needs (1970). As noted in Section II, the categories of need within Maslow's Hierarchy, were expected to have a relevance to this study on at least two counts: first, quality of life is attaining needs that particularly contribute to life's satisfaction and therefore needs theory has a relevance; and secondly since Maslow's theory formed the basis of some major clinical
models of care, clinical application of the findings would be served by reference to Maslow where appropriate.

Beyond this it was hoped that some different conceptual framework might emerge from the data. However, as the research and the analysis proceeded the relevance of the Maslow Hierarchy to the findings became more and more evident, not only as regards the categories of need, into which the terms used by patients naturally fell and the importance that patients gave to these terms, but as regards at least some of the hierarchy. For, when patients were largely overwhelmed with thoughts of physical and emotional discomfort they did not talk about other aspects of living; when drowning in a sea of physical or emotional distress, music for example, is not likely to feature highly in need awareness even for one who loves it. Conversely when the basic needs were met and a degree of comfort attained then it was possible to want and to enjoy other things. Many respondents equated their renewed interest in life with the physical comfort they had received. As far as the sections on relationships (Section VI), identity (Section VII), and meaning (Section VIII) are concerned, hierarchy is neither implied nor denied. They have been placed in a position commensurate with the proportions of respondents who spoke of them.

This research with dying patients has therefore presented an opportunity to affirm some of the relevance of Maslow to the lives of dying patients to an extent that was not at first fully anticipated. This has been an opportunity that is perhaps not easily obtained for in most research in modern industrialised and relatively affluent societies, the majority of
people are likely to be consciously functioning at levels beyond the basic. For at least some of the respondents in these samples, they have been strongly and consciously engaged with the matters of very basic physical comfort and survival that are often taken for granted.

As will be noted, the terms used in the categories of quality of life factor are slightly different from those of the Maslow Hierarchy of Needs although they incorporate similar conceptual ideas; in a subjective study it seemed important to focus upon terms used naturally by respondents. Thus Maslow's first category of 'physiological needs' becomes physical comfort; the outcome of their satisfaction. And in the same way his 'safety needs' become feelings of emotional comfort and security. Maslow's third category is 'belongingness and love' both of these terms have featured in the data; this theme is described as warm supportive relationships of love and belonging. His final two needs for 'esteem' and 'self-actualisation' have been referred to by patients in a cluster of concepts best expressed in two terms that have been used; 'acceptable identity' and 'purpose in life'.

It was anticipated in a study in which needs theory would be relevant that 'reference groups' and 'expectations' would feature in the data collected. What was not so expected was the insight that would be gained into the patients' perceptions of the care received in organisations other than those in which the research was carried out. Each patient in the hospice had experienced care in at least one other hospital, and some in many during the long progress of their cancer and its various treatments. Much of what mattered to their quality of life at the time of
the research, and the reason for it mattering, was often spontaneously related to past experience. Whilst there was a great deal of satisfaction with the care received in the research venues, the picture that emerged of other situations was at times very disturbing and indicates that there is no cause for complacency with health care. These references are reported in each section.

Each of the five sections on the findings is arranged into two halves, not always two chapters. The first half begins with a brief introduction to the concepts to be discussed and this is followed by a background discussion in which other studies are cited. The findings are then presented in relation to the relevance of these concepts to the quality of life of respondents. The focus of the last half of each section is the clinical situation and how these concepts particularly relate to quality of life and the provision of care. This is based upon a considerable amount of spontaneous comment that was offered in response to the quality of life question. These findings suggest that there should be several specific aims in care if the overall goal is to enable patients to experience maximum quality of life. These aims are discussed as they relate to three main concepts - the organisation of care - the expertise of care - the interactions of care.

These concepts have already been discussed as part of the historical development of Section I. The aims of care may be defined as the guiding principles of care around which the organisation does, or should, revolve. Organisation has implications for structure in terms of environment and facilities provided, as well as for systems and rules of
care, staffing levels, provision of professionals, and education and support of all staff. Expertise relates in the context of this discussion to the provision of skills appropriate to the particular needs of these patients. These concepts are related through the response to the quality of life of patients.

The qualities of interaction within care involve far more than efficiency in completing a procedure, they include emotional warmth, respect for the patient, empathy, and a stability of the giving of the self to the patient. Wright (1990a) describes this aim in nursing as a type of caring that contains elements that are both 'heroic' (Ianara, 1981) and 'presencing' (Benner, 1984):

'beyond ... the efficient completion of a simple act. ... It contains commitment to pursue that caring which overcomes the defined limits of job descriptions ... having a heroic component (and) ... "presencing" the being with skills of the nurse which make the patient feel not only cared for but cared about ... The way the patient is touched and moved, observed and listened to, comforted and relaxed, taught and informed, valued and respected - all these attributes combine both instrumental and expressive skills which not only help patients but heal them'. (P. 46)

Many patients in this study differentiated the quality of interaction from the task that was performed; the way they were touched, moved and informed was an important factor in their quality of life.
Finally each section ends with a conclusion which summarises the relationship of the concepts under discussion to the quality of life of the patient and to the aims of the research. Namely:

1. Identification of quality of life factors chosen by terminally ill patients.
2. Understanding the quality of life context.
3. Presentation of the findings in a manner likely to help the clinical situation.
SECTION IV

QUALITY OF LIFE AND HAVING PHYSICAL COMFORT
The discussion of the response starts with the finding that physical comfort was all important to the quality of life of the patients in these samples. In a situation such as theirs in which bodily comfort was being destroyed by disease, physical comfort meant adequate symptom control in which, very often, the feeling rather than the source of discomfort was removed. Forty-five patients (86%) in the hospice 'random' sample and 15 (68%) in the hospital sample, spoke of the importance of physical relief to quality of life, this was in terms of relief achieved or hoped for. The higher proportion of those who spoke of comfort and discomfort in the hospice sample is likely to reflect the situation in which the hospice, as a specialist centre, particularly admitted patients who presented problems of symptom control.

Patients spoke with considerable intensity, of the discomforts of past or present; the chief of which were, pain, nausea, vomiting, and constipation. Other symptoms had also brought misery and these included diarrhoea, anorexia, paralysis, weakness and insomnia. Since patients in the hospice were interviewed within a few days of admission some were in the process of obtaining full pain control, and pain recurred at times; for others, the memories of pain were fresh and distressing. The 'pains' suffered had a devastating effect upon quality of life, frequently blotting out everything else that mattered. In strong contrast, symptom control provided great increase in quality of life, not only because of
the enormous relief experienced but because this also provided a basis for fuller living. This chapter explores this situation.

BACKGROUND - THE PREVALENCE OF DISTRESSING SYMPTOMS IN THE DYING

The experience of physical distress of many of the patients in these samples was consistent with other research findings. Over the last quarter of a century studies have indicated that physical distress is a common experience of the dying. Early studies included those of Aitken-Swan (1959), Exton-Smith (1961), Hinton (1963), and Saunders (1961). Exton-Smith estimated that 13.6% of a series of elderly patients, with a variety of diseases, had moderate or severe pain and 7.7% had other symptoms. Hinton (1963) studied the physical distresses of a sample of dying patients in a teaching hospital, most of whom had a malignant condition, and found that pain was the most common condition in 66%; symptom control was far from complete. Saunders (1963:113) undertook research in a hospice, the same venue as this study, and noted, 'many patients have had a great deal of pain before admission'.

A decade later Cartwright and Anderson (1973) undertook a wide ranging retrospective study of a random sample of 785 recent deaths in twelve areas of England and Wales; they obtained information from relatives and medical and nursing staff and noted the many distressing symptoms suffered by patients in hospital as well as in the home. The subsequent influential research report queried whether the care given in hospital was appropriate to the needs of the dying, and whether the relatives and community services were able to give the intense skilled care required by those
dying at home. The picture therefore looked very bleak wherever the individual died.

This situation is not only bleak as regards the distress suffered, but also as regards its consequences for daily living. Maslow (1970) refers to the physiological needs as the most pre-potent of all the needs; pre-potent in that the painful stimulus accompanying physiological deprivation normally has priority over the stimuli relating to higher needs. Someone who is drowning in a sea of pain is unlikely to be strongly conscious of social relationships, or the need to be surrounded by things of aesthetic value; they cannot rise up the Maslow hierarchy. This is consistent with clinical experience in which it is found that pain can expand to fill the patient's whole horizon (Twycross, 1975a). Cleeland (1985) states:

‘Many adults function quite effectively with background levels of pain which, for the most part, do not distract them. As pain increases, however, it passes a threshold beyond which it can no longer be ignored. At this point it becomes disruptive to many aspects of an individual's life. At a very high level of severity, pain generally becomes a primary focus of attention and prohibits most non-pain-related activity. (P. 88)

Within recent years the possibilities for symptom control have improved, for knowledge has increased, and when used appropriately has resulted in better relief of physical distress, particularly that of pain (Lamerton, 1980). But, despite the availability of knowledge there is still disturbing evidence that dying patients continue to suffer a range of
poorly controlled symptoms. This evidence is found in hospice records of the state of patients on admission (Saunders, 1984. Regnard, 1986), and in research in hospital and home (Hockley, 1983; Drury, 1984; Parkes, 1978). Like hospital staff, many General Practitioners do not find it easy to cope with pain. In a survey of 196 GPs 30% frequently, or always, had problems controlling pain (Haines, 1986).

Recently a wide-scale National Hospice study was conducted in the USA. Morris with others (1986) studied over 1700 cancer patients from 40 different hospice programmes, in both home care and institutional settings, and from 14 conventional care settings. Only 16% of patients were pain free in the last weeks of life and 18% were in persistent pain. At the time of entry to the study 12.1% of patients reported pain as 'horrible' or 'excruciating'.

Pain is the symptom that is most often associated with cancer but it is only one of many inter-related symptoms experienced by patients. Patients admitted to specialist units are found to suffer from a range of poorly controlled symptoms (e.g Table 6.1 - over page, Hanks, 1983). There was very little change between these two sample years. This range and extent of symptoms has been found by others both inside and outside of special units (Haram, 1984; Hockley, 1983).

Wilkes (1984) took a sample of 262 deaths in a ratio of two hospital deaths to one home one, so as to follow the national pattern of the place in which people died, and found the same range of poorly controlled symptoms. Wilkes obtained his data from relatives, doctors and nurses.
These findings show that there is still much to be achieved in relieving the many distresses of the dying. The survey concluded that only a minority of health carers delivered exceptionally good care as far as symptom control was concerned, and some provided care that was exceptionally bad.

Table 6.1 Most common symptoms experienced by patients on admission to a specialist unit * (percentages).

<table>
<thead>
<tr>
<th></th>
<th>1981</th>
<th>1978</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>69</td>
<td>54</td>
</tr>
<tr>
<td>Anorexia</td>
<td>66</td>
<td>52</td>
</tr>
<tr>
<td>Constipation</td>
<td>46</td>
<td>43</td>
</tr>
<tr>
<td>Dry Mouth</td>
<td>41</td>
<td>45</td>
</tr>
<tr>
<td>Nausea</td>
<td>38</td>
<td>31</td>
</tr>
<tr>
<td>Vomiting</td>
<td>32</td>
<td>27</td>
</tr>
<tr>
<td>Insomnia</td>
<td>37</td>
<td>19</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>34</td>
<td>30</td>
</tr>
<tr>
<td>Oedema</td>
<td>32</td>
<td>34</td>
</tr>
<tr>
<td>Cough</td>
<td>26</td>
<td>28</td>
</tr>
</tbody>
</table>

* Sir Michael Sobell House, Oxford. Taken from Hanks, G.W., 'Management of symptoms in advanced cancer'. (Update P. 1691)

It is not only the frequency and degree of pain and range of symptoms that contribute to the suffering, it is also the length of time that symptoms have been endured. In their study of 100 patients admitted to a hospice, Twycross and Fairfield (1982) found that 73 had experienced pain for more than eight weeks, and 57 for more than 16 weeks. Over half of these patients described their pain as 'severe', 'very severe' or 'excruciating'. It is difficult to fully appreciate the suffering behind these statistics, but it must have had a considerable negative impact upon quality of life.
Variables that Influence Statistics

The variables that may influence statistics are many when it comes to research into the physical distresses of the dying; caution must therefore be taken when comparing one set of findings with another. These are: (1) Location of research (2) The nature of the disease (3) The stage of the disease (4) The research method. These will be discussed in turn.

1. Location of Research  The location of research has a bearing upon the types of symptom likely to be found in a sample of patients. For example, specialist terminal care units such as hospices may admit a higher proportion of patients with distressing symptoms than a hospital just because they have expertise in symptom control. There may be other hidden factors with regard to the reason for admission; for example a high proportion of patients in a community hospital suffered nausea, vomiting and incontinence, for they were admitted because these were the symptoms that presented relatives with the most difficulty (Drury, 1984).

2. The Nature of the Disease  The nature of the disease has a relevance to the prevalence and severity of distress. Distressing breathlessness is particularly associated with heart and lung disease, malignant or otherwise, and can cause as much if not more suffering than pain (Hinton, 1963; Hockley, 1983). The incidence and type of symptom is likely to vary with the type and the site of the disease. In a one week survey of all patients at a cancer centre, Foley (1979) found that 29% of all patients had pain but the prevalence varied with the site; from 85% for those with primary bone tumour, 80% with oral cancer, and 70% with genito-urinary cancer, to 5% with leukaemia. Wilkes (1974) studied 600 consecutive
admissions to a hospice and found that 82% of patients with cervical cancer and 75% with gastric cancer had pain, compared with 44-59% of those with cancer of lung, rectum and breast. This situation accounts for the finding that whilst some cancer patients experience severe physical distress others remain free (Twycross, 1975a).

There is some indication that a higher proportion of cancer patients may experience physical distress than those suffering other diseases. Doyle (1983) compared a sample of cancer patients with a group of patients with a variety of other diseases. He found that 87% of the cancer patients had pain compared with 65% of the others, and that this order of difference extended throughout the range of common symptoms. Oster (1978) used nursing notes and analgesic records, and found that 72% of terminal cancer patients had pain compared with 45% of patients dying of other diseases.

3. The Stage of the Disease The stage of the disease is another variable that has to be considered in comparing statistics for it has been shown that the range and severity of symptoms increase as the disease advances. Hinton (1963) showed in a mixed group of patients that there was a rise in distress in the last week of life. One of the aims of the United States Hospice study (Morris 1986) was to identify the shifts in prevalence and severity of pain as death approached; they found that 17% of patients were said to be in severe pain in the last week and this increased to 25% in the last two days. This situation has a relevance when statistics are compared between groups of patients defined as terminally ill, for this definition may vary in research. For example, the patients in Hinton's
study (1963) were thought likely to die within six months, those in Hockley's study (1983) were thought to have only three months to live.

4. Research Method The research method may also influence the statistics obtained. As discussed in chapter 5 many points have to be considered before undertaking research with dying patients. Pain and other physical distress is a very subjective experience but the degree of general deterioration may make it difficult for patients to adequately express their pain in the later stages of the disease. For this reason some studies have approached the identification of physical distress indirectly, through asking the opinions of relatives and professionals. However, subjective and objective definitions do not necessarily agree with each other (Morris, 1968; Wilkes, 1984). A method one stage further removed from the patient is to assess pain through the amount of analgesics prescribed. (Goldberg, 1973; Oster, 1978), the assumption here is not only that the objective assessment is close to the subjective, but that the amount of analgesic prescribed is appropriate to that pain.

CONCLUSIONS
Although the review of research studies presents many difficulties, the consensus of opinion is that there is a high degree of suffering experienced by dying patients. Bonica (1984) used the combined findings of many studies and estimated that 55% to 90% of those who are terminally ill have pain. Regnard (1984) estimated that 25% of all patients dying of cancer in the United Kingdom do so without obtaining relief from severe pain. This figure represents 33,000 people each year.
Physical comfort was spontaneously stated to be important to quality of life by 45 (86%) of the hospice 'random' sample and 15 (68%) of the hospital sample. The emphasis on physical comfort was not surprising since many patients had suffered a variety of symptoms; some had been referred to the hospice for specialist symptom control. Table 6.1 indicates the symptoms suffered on admission by the hospice 'random' sample, and Table 6.2 the symptoms discussed by this and the hospital sample at interview. The symptoms in the hospice 'random' sample ranged from one to ten per patient, the model group of patients having six symptoms each. As discussed in chapter 5 only patients who were relatively fit were able to be interviewed so these statistics are likely to considerably underrepresent the 'pains' of all dying patients there.

Table 6.1 Patients Reported Symptoms on Admission - Hospice 'random' sample. (Percentages)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>56</td>
</tr>
<tr>
<td>Bowel Problems</td>
<td>54</td>
</tr>
<tr>
<td>Anorexia</td>
<td>48</td>
</tr>
<tr>
<td>Nausea and Vomiting</td>
<td>29</td>
</tr>
<tr>
<td>Incontinence</td>
<td>29</td>
</tr>
<tr>
<td>Cough</td>
<td>25</td>
</tr>
<tr>
<td>Insomnia</td>
<td>23</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>15</td>
</tr>
<tr>
<td>Mouth Problems</td>
<td>13</td>
</tr>
<tr>
<td>Oedema</td>
<td>12</td>
</tr>
<tr>
<td>Weakness</td>
<td>10</td>
</tr>
</tbody>
</table>

Percentages do not sum to 100% - many patients experienced more than one symptom.
Table 6.2 Types of physical distress spontaneously reported at interview by hospice 'random' and hospital samples

<table>
<thead>
<tr>
<th>Types of Physical Distress</th>
<th>Hospice n = 52</th>
<th>Hospital n = 22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>25 (48%)</td>
<td>7 (32%)</td>
</tr>
<tr>
<td>Insomnia</td>
<td>11 (21%)</td>
<td>2 (9%)</td>
</tr>
<tr>
<td>Weakness</td>
<td>10 (19%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Bowel Problems</td>
<td>9 (17%)</td>
<td>2 (9%)</td>
</tr>
<tr>
<td>Immobility</td>
<td>9 (17%)</td>
<td>4 (18%)</td>
</tr>
<tr>
<td>Anorexia</td>
<td>8 (15%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Nausea and Vomiting</td>
<td>7 (13%)</td>
<td>1 (9%)</td>
</tr>
<tr>
<td>Poor eyesight</td>
<td>5 (23%)</td>
<td>2 (9%)</td>
</tr>
<tr>
<td>Urinary Problems</td>
<td>1 (2%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Oedema</td>
<td>-</td>
<td>2 (9%)</td>
</tr>
<tr>
<td>None discussed</td>
<td>7 (13%)</td>
<td>7 (32%)</td>
</tr>
</tbody>
</table>

* Percentages do not sum to 100% - many patients reported more than one physical distress.

Types of Physical Distress: Distress was of different types; all diminished quality of life. The pain that some patients had suffered had been of considerable severity:

Mr PD (Hospital) 'I was in such pain. I said I will endure anything to get rid of the pain'.

Mr A (Hospice) 'The main factor is getting rid of my pain, it nearly drove me mad. I can stand pain but it was like ten toothaches. You could get no relief.

Mrs G (Hospice) 'I never knew what pain was like until this started on me'.
Pain, for some, had been long in duration. Mr D (Hospice) had suffered pain for eighteen months. It was not surprising that his first response to the quality of life question was, 'Some day to do without this pain'.

Mrs L (Hospice) had also experienced months of pain. She, like others, had been admitted for symptom control. In these circumstances it is not hard to sense the desperation lying behind her words:

'Here is the last resort for trying to minimise the pain ... perhaps what they are doing now might keep it free for a few months, maybe I will have to come in again'.

Mild but continuous pain could also be distressing and diminishing of quality of life. Mrs T (Hospice):

FEELINGS ABOUT QUALITY OF LIFE AT PRESENT

Delighted _______ X _______ Terrible

'The only thing, it's the same feeling every day in your stomach - that little miserable pain'.

When cancer has invaded bone then any movement can be very painful. Mrs R (Hospice) had this recurring problem:

'I can't help holloring (howling) when they lift me'.

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Gastro-intestinal problems were distressing and worrying. The inability to eat, or to eliminate is not only physically unpleasant but threatens deep survival instincts.

Mr M (Hospice) Quality of life - 'That's hard to say because I woke up not feeling like breakfast'.

Mrs T (Hospice) 'Getting the bowels right'. (First comment).

It is perhaps easier for professionals to dismiss weakness as inevitable, and less destructive than pain or vomiting, but its effects can be as profound for the patient:

Miss C (Hospice) 'They have taken all my breast, that doesn't worry me, but this weakness does'.

Mrs PJ (Hospital) 'This terrible weakness'.

When a patient suffers with advanced cancer it is all too easy to assume that all pain is directly due to this disease. Twycross (1982) found that 80 out of 100 cancer patients had more than one kind of pain. As in this study, distressing pain came from the cancer but also from other conditions such as arthritis, as well as the stiffness resulting from lying in bed and from being unable to move.

Mrs GD (Hospice) 'Physical comfort is very important when you are disabled'.

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Mr F (Hospice) 'If you are sitting down for most of the day you easily get tense around the spine'.

People's expectations with regard to symptom control played a part in their assessment of quality of life. Assessment rose with partial success and the hope that this would soon be complete. Expectations could also be low. For example, Miss E (Hospice), linked her quality of life measure with her somewhat low expectations of what could be done to help. She still had some pain, but as she completed the scale she said:

'Somewhere in the middle - I suppose people are doing all they can for me'.

Another form of distress associated with symptoms stemmed from their secondary effect. For example, quality of life was reduced for Mrs PK (Hospital) not only by her frequency but by the impact that she perceived that this had on others:

'Quality of life, it's very difficult to say, because I have diarrhoea and water trouble so have to have the nurses running round. In the night it is very trying for the nurse to be running around with a commode'.

Physical Distress can be Overwhelming

There was much evidence from the statements made in the data to suggest that uncontrolled symptoms had a major diminishing effect on quality of
life. This was shown in the quality of life visual analogue scales. Out of
the 22 scales that were completed four were scored in the lower quarter,
and in each case pain or other physical distress was cited as the major
factor. For example:

Mrs G (Hospice) was beginning to experience a return of pain and measured
her quality of life accordingly:

FEELINGS ABOUT QUALITY OF LIFE AT PRESENT

Delighted Terrible

' Get rid of the pain - its the pain ' 

Physical distress could take over the whole of life, blotting out all else
that normally mattered to the sufferer, particularly when there was a
range of related symptoms that had been allowed to build up. Mr PC
(Hospital) had been in a state of utter misery and this experience had
been shared by others in the samples. His pain had produced prolonged
insomnia, and the morphine given for his pain had resulted in severe
unrelieved constipation, which in turn had led to anorexia. This vicious
circle had continued until life had not been worth living.

'Over the years I have suffered so much pain, that bad I have tried to
commit suicide three times - have had no sleep. The morphine is
killing me, making me constipated. I have sat on a toilet crying from
5.0 to 5.45 in the morning - a fortnight and have not been. You can't
eat when you are blown out. People suffer; they could finish it'.

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GOOD SYMPTOM CONTROL AND IMPROVED QUALITY OF LIFE

Comparison of a better present with a worse past was the basis of many of the higher measures of quality of life, whether made by statement as Mr N (Hospice) whose first response to the quality of life question was:

'These last few days I have been constipated - today I went twice, and that has been the biggest satisfaction of my life'. (First response)

or by visual analogue scale. Symptoms and their relief featured in 16 (73%) of all quality of life assessments on these scales. Mr A (Hospice) has been noted at the beginning of these findings as having had 'pain like ten toothaches' before admission. Relief of this pain featured in his quality of life assessment:

FEELINGS ABOUT QUALITY OF LIFE AT PRESENT

Delighted [X] Terrible

'Being here has changed me into a happy person. I was terrible'.

Both the statement of Mr N (Hospice) and the scaled measure of Mr A (Hospice) illustrate that whilst symptom control remained constant as a quality of life factor, the measurement of quality of life could fluctuate quite suddenly with change in circumstance.

Symptom Control and Expanded Living

Another important indication of the relevance of symptom control to quality of life was seen in those whom it had released from crippling
distress to live more fully once more. Mrs F was one of 16 (31%) hospice patients who spontaneously stated that some of their abilities had been restored by symptom control. On admission she had been very limited by discomfort. As she gradually felt better, her energy no longer being taken up with combating pain, she could engage once more in the things that were most important to her; she could begin to meet her higher needs.

FEELINGS ABOUT QUALITY OF LIFE AT PRESENT

Delighted

Terrible

‘At the moment health better - a little bit more useful’

CONCLUSIONS

The findings of this chapter indicated that physical comfort obtained through good symptom control was fundamental to the quality of life of these respondents, a large proportion of whom had at some time experienced a range of unpleasant physical symptoms in which pain predominated. These experiences had remained disturbingly in the memory. Patients’ comments have illustrated the devastating effects that such distress can have upon quality of life, reducing quality to a point where life no longer seemed worth living. Conversely physical comfort produced by good symptom control has had the power to dramatically change quality of life for the better, not only by relieving distress but by providing a basis for fuller living and the possibility of awareness of higher needs, despite the remaining presence of the disease process. There is a consistency here with the Maslow (1970) hierarchy of needs in which the satisfaction of physiological need forms the basis of all else.
Expectations of what could be done have had a relevance to quality of life assessments; expectations can be low. When past experience has been a point of reference, and this has been intense distress, then the quality of life measure can move dramatically. Symptom control itself was an important quality of life factor important to all, all of the time. The attaining of physical comfort had become a social concern, for these respondents for they had come to a point where their own efforts at maintenance comfort were no longer of avail. Effective symptom control becomes a symbol for physical comfort when it either removes the cause of the distress or masks it so that the patient is unaware of its presence; either way it is vitally important to quality of life.
The last chapter has looked at the physical distress of respondents and noted the importance of effective symptom control to comfort and to quality of life. Since patients cannot achieve this by their own efforts, physical comfort must stem from the efforts of others. This chapter uses the remaining response on this subject to look at issues in care which help or hinder this aim. The response from patients indicated that if quality of life was to be the goal of care then the following aims in care are important:

1. Appropriate symptom control.
2. Skilled nursing care.
3. Choice and control for the patient.

APPROPRIATE SYMPTOM CONTROL

Since all of the patients who took part in the research were comfortable enough to become respondents, and many had previously been in severe distress, it may well be asked why their relief had not come sooner, or why their pains had ever become so bad. One reason for poor symptom control in chronic disease is the orientation of professionals to cure, for the principles that govern the approach to the pain of the acutely ill curable patient are different from those that govern the approach to those who are chronically ill, with a disease such as cancer. Regnard (1983) outlines some of the differences between treating acute pain and the kind of chronic pain suffered by the patients in these samples:
'Pain is not a simple sensation but a complex physical and emotional experience. This is particularly true in the chronic pain of cancer, which is quite distinct from acute pain such as that due to a fracture. Chronic pain is often difficult to describe or locate, and is seen by patients as unending meaningless endurance which progressively takes over their lives. It is relatively easy to become proficient at dealing with simple acute pain in the short term. The very complexity of chronic pain, the length of time over which it needs to be controlled means much greater skill and care is needed for its treatment'. (P. 1)

To be effective therefore, symptom control has to be appropriate to the situation of the patient.

Although it is unlikely that these respondents knew of the principles of treating chronic pain it became clear from their comment that on some occasions at least, these had not been applied and that their suffering was increased by apparent failure to apply knowledge gained over the last twenty years. One important principle in symptom control is that the chronic pain of terminal illness needs to be adequately treated as soon as it experienced, and not allowed to build up. This had not been the experience of some of the patients. Mrs S (Hospice) was one of these patients. She had learnt from bitter experience that it takes time to redress this situation:
'The pain has been bad, it's now better but still getting rid of it - it's a job to get rid of anything taken root'.

And another was Mr PC (Hospital), speaking of the time before his admission: 'I had the pain - getting worse - didn't seem to take any note'.

Another principle is to give medication appropriate to the pain and to the individual. This had been difficult for the doctor of Mr A (Hospice):

'My doctor did his best but the drugs didn't suit me. I was on Diamorphine and it gave me hallucinations and made me worse'.

By implication the doctor of Mr A (Hospice) had also failed to seek specialist advice early enough when there were difficulties, for by the time help was sought the pain had become severe.

A further principle of good symptom control is that appropriate medication must be appropriately timed. Chronic pain needs to be relieved and then prevented from recurring, for it will always be in the background waiting to break through into consciousness. The aim is that when regular prevention is practised the result will be an erasing of even the memory of pain (Saunders, 1984). This cannot happen if the patient has to experience the return of pain and then ask for relief each time. This is a different approach from that used with acute pain when it is necessary to know if pain is still present. Mr A (Hospice) 'with pain
like ten tooth-aches' (as noted in chapter 6), had learnt that prevention
was vitally important to his quality of life:

'Having the medicine on time and efficiently given. It's so important
because of the pain - that's most essential'. (First response).

Unless patients are on long lasting drugs a particular danger point is at
night when nurses may be diffident to wake those who appear to be
peacefully sleeping. Two patients spoke of waking in severe pain that was
then difficult to control. For example Mr PC (Hospital) had experienced
such an incident and had then asked the night nurses for an assurance
that they would wake him; one nurse had promised to do so but another
expressed diffidence. This was intolerable to him and he was seeking to
discharge himself:

'I have had a bit of a do over the night-time business. I said, "If I
am sleeping, wake me". One agreed and the other didn't - this
business of not being on time. I said, "I can understand if you are
short of staff. If you can't do nothing I might as well go home".'

It appeared that there must have been some failure of monitoring or
communication in the situation of Mr CD (Hospice), for his symptom
control had become completely out of hand before he was admitted, and
this was confirmed in staff discussion (although not necessarily the
dosage that he stated that he had been taking). He said:
'I was taking 30mg Morphine tablets, five at a time, and sometimes in between because my doctor said here are Morphine tablets, take them as you need them. I was sick and effected by them'.

Little response was available from the majority of respondents as to why their physical distress had developed, and they were not asked, but the comments of the few noted above indicate that it is likely that at least five major principles of symptom control in terminal care had not been applied at one time or another, resulting in much distress. These kinds of failure have been found to stem from lack of knowledge (Wilkes, 1984) and lack of confidence to use powerful drugs, from diffidence to consult experts and thus admit a need (Wilkes, 1984), and from failures in communication within hierarchical systems, when the most junior medical staff may not have the expertise to cope. Ahmedzai (1982) found that up to 50% of junior doctors reported inadequate training in symptom control in the dying, and up to 30% of medical students graduate without ever having participated in the management of dying patients. These are to be the doctors closest to the patient, those who must negotiate between patient, nursing staff and consultant. In the medical student research associated with this project (Appendix 5) one student said:

Student F 'In the NHS it is hard for the junior doctor to know what the consultant thinks because there is such a big gap (in hierarchy) - the junior doctor has to do the best he can for the patient'.
There may be failures in communication with the patient; a good communication relationship depends upon how much patients are prepared to discuss their problems. Doyle (1983) found that as many as 50% of the problems troubling patients may not be reported. The reasons for this included, putting on a brave face, protecting staff from knowledge of failure, and dislike of drugs (Twycross, 1981; Cleeland, 1985). As noted in the last chapter, patients' expectations can play a part; Miss E (Hospice) did not complain of her pain because she felt that as much as possible was being done for her. She also assumed that the staff knew all about it:

'I have a lot of pain - take it for granted that people know all the time. I have had it so long'.

Patients may not feel able to communicate distress if they perceive that the professional is diffident to ask about symptoms, or is creating barriers. Wilkes (1984) notes that doctors who have difficulty with symptom control tend to ignore the patient on ward rounds. As Illich (1976) states, our culture denies the reality of pain because having made it a technical matter, its existence is seen as a sign of failure. In the interaction between doctor and patient, the doctor's lack of confidence or unwillingness is recognised by the patient who is then less willing to complain. In the communication research (Appendix 6) that was undertaken as part of this study, patients' perceptions of the doctors professional competence and willingness to enquire were both cited as criteria for communicating with doctors. For example, Mrs XE (Hospice) would tell the doctor of her symptoms 'Especially if he asks'. Good communication also
requires appropriate use of language between people; language can cloud as well as clarify issues, and can be used to both ends.

There are many reasons therefore why it cannot automatically be assumed that those who have trained and worked mainly with the acutely ill have competence in dealing with the distresses of the dying, for they may not have the necessary confidence or experience. Hinton (1963) compared the symptoms of a group of seriously ill patients with those of patients who were dying, and found that the symptoms of the latter were greater in incidence and severity.

The researcher was once approached by an individual who wished to set up care facilities for the terminally ill based upon knowledge derived from some years of good acute work. As the conversation progressed it soon became clear that this experience had provided little insight into the situation that was likely to be encountered, or into the range of facilities, in terms of human and material resource, that would be required to meet it, even if symptom control was to be the sole objective. A consequence of this kind of situation is that although the knowledge of symptom control in terminal care has been available for some years, patients may be surrounded by professionals whose skills are inappropriate to their condition.

As discussed in chapter 3, recent years have seen the development of specialist services for the terminally ill that will provide advice to professionals when asked. Both areas in which the research was undertaken were covered by such service. For some patients, for whatever reason
(lack of knowledge on the part of professionals, lack of willingness to consult, breakdown in team communication), their bad pain experiences had arisen because their pain had been allowed to build up, and specialist advice had not been sought early enough. They had not been surrounded by the appropriate skills.

In contrast to some of the despairing statements that have been noted was the confidence of Miss ID (Hospice) for she felt an effective relationship had been formed with a doctor who had the appropriate skills to deal with her situation:

'Here they have medication down to a fine art. Everyday I am asked, am I in pain, did I sleep well - would you like a stronger sleeping pill? ... there is an immediate reaction from the doctor. He is very positive.'

SKILLED NURSING CARE

There was an emphasis in the response, on skilled nursing as very important to quality of life; it enhanced quality of life through the comfort that it both gained and maintained. There were many references to the importance of nurses to quality of life, approximately half in each sample made some comment; 20 in the hospice 'random' sample and 5 in the hospital specifically related nursing care to physical comfort. For example: Mrs PB (Hospital) said, 'The nurses try to cheer you with making you comfortable'.
A greater proportion of men, in each main sample made such references: (12) 55% of men in the hospice 'random' sample compared with (8) 27% of women, and (3) 43% of men in the hospital sample compared with (2) 13% of women. Since nursing care has a relevance over and above that of physical comfort some of these references appear in other sections.

It was vitally important to the quality of life of patients that they were handled gently and skilfully, particularly those who were cachectic (emaciated) and frail, and those with bony metastases or painful joints:

Mrs E (Hospice), 'No roughness'.

Skilled positioning of the patient, and attention to pressure areas was also important:

Mrs I (Hospice), 'Comfortable chairs, my own particular problem is pain - the pillow in the back of the chair, not everybody thinks of that - it is important to me'.

Mr O (Hospice), 'When I came here I had a lot of bedsores because in my estimate they were neglected - these people are doing them properly now'.

Change of position was also important - aching muscles contributed to the pain experienced. Mrs N (Hospice) had been left sitting by the window for too long - this was where she loved to be for it brought interest into
her life. It is not known why she did not ask to be moved but this was her experience:

'Today they left me over 4 hours in a chair by the window. It was far too much and I felt like crying'.

Warm baths and massage eased the stiffness of immobility and induced relaxation. The importance of baths to comfort was mentioned by 5 (10%) of the hospice 'random' sample. For example:

Mr A (Hospice), 'I had a lovely blanket bath this morning'.

Mr F (Hospice), 'It was lovely to have an oil bath today. I did enjoy it and went to sleep for a little while in it - a volunteer lady has offered to give me a massage'.

Mr K (Hospice), 'Lovely hot bath and shave this morning - made me feel fresher'.

The skilled care that is appropriate to meeting the comfort needs of the dying patient demands adequate time, for very ill people cannot be hurried. Staffing levels need to be appropriate. There was some evidence that time did not always seem to be available. The hospice had its periods of rush particularly as it tried to get through many of the nursing procedures early in the day to allow the maximum time for undisturbed visiting. Mr R (Hospice):
'I hate being hurried and they hurry you in the morning - have a bath and you are lifted in and out - you should have a bath in your own time - not a lickety spit and you are out. But that is only a little complaint but it is one'.

Four of the comments on busy staff related to the experience of hospice patients in past hospitals. For example:

Mrs V (Hospice), 'Big hospitals haven't any time for you - here they seem to have time'.

Mr K (Hospice), 'The nurses in Y are different from here, if I wanted them to change me, or clean me, I would have to wait ... there you were just like a number'.

The other comments came from the hospital, from almost half of the patients (10), and from seven of the ten wards. For example:

Mr PE (Hospital), 'We need more nurses on at night time - only have three. They are at their wits end'.

However two patients considered that some of the rush was due to the inappropriate use of nursing staff:

Mrs PK (Hospital): 'There isn't the after care there should be because the nurses have too much to do. They help with dinners and do all kinds of little things which a nurse should not have to do. They
are trained people ... Sister, she has been here all her life, she shouldn’t be doing what she does with her qualification. I think a Sister is above little petty things - she should not wait, she should tell people what to do ... a different generation ... there are an awful lot of patients. While they are helping with dinners someone is not getting the attention they should get - they have long hours, the system is wrong ... I have been in three times this year and the nurses all help with dinners’.

Mr PD (Hospital), 'Sister is off today - they are always busy. Poor staff nurse she has had to share her job today. They used to have cleaners, I suppose they have cut them down. Even the nurses take the bottles of urine away now. In the old days it was an orderly’s job. They do it so cheerfully and willingly. I try not to make demands'.

Whilst the reason behind certain actions may not be fully appreciated by the patient, it is a matter of public concern that nurses’ skills are not used to the best advantage (e.g. Nursing Standard, Jan10:6).

CHOICE AND CONTROL FOR THE PATIENT

Eleven (21%) of the hospice ‘random’ sample and 7 (32%) of the hospital sample indicated that quality of life was enhanced when the approach to symptom control and general comfort included characteristics that can be defined as a focus on the patient as an active partner in care, rather than as a passive recipient of care. Partnership for patients meant their involvement in decisions related to the means of producing physical comfort. Some patients expressed the importance of being given choice in
symptom control, and others in daily activity that affected their physical comfort. This was not usually a case of a demand from the patient for overall control, but rather a desire for patient and staff to work together towards that which was most appropriate. Partnership in symptom control involved supplying the patient with information upon which a decision could be made. To have information is to have the potential for power and control in any situation. Without knowledge of what is going on and why it is going on there is helplessness to intervene or express preference.

Despite the full knowledge that his illness was going to kill him, Mr F (Hospice) could find some pleasure in being involved in his own symptom control; the focus was on his understanding of the situation as well as his control. He started off with the emphasis on the 'we'; his eyes lit up as he said this:

We are experimenting a lot - the trouble is that my cancer is squeezing the bowel - and I have two blockages further up - there are two points of danger for getting into trouble'.

This form of partnership was also important to Mrs F (Hospice). She was able to monitor progress and understand the problems:

'When I came in here they said they would get my ostomy working and my catheter right and they have. I feel a bit weaker though and the doctor said they could not do anything about that, he would expect it'.
For two patients a failure by nurses to take them seriously resulted in distress. As has been noted in chapter 6 one hospital nurse seemed afraid to use discretion in giving analgesics at night. Nurses in the hospice did not exercise flexibility with regard to aperients for Miss C (Hospice):

'Too much aperient has made me uncomfortable - no sleep at night - begged the nurses not to give it last night but the nurses said only the doctor could say amount - upset me so much last night - nurses had to change sheets and nightie - I knew they were giving me too much'.

Sometimes it is imperative that the patient make a choice. This was the situation for Mrs FD (Hospice), and the choice was a painful one, but she derived some satisfaction from the knowledge that she had made it, and had her priorities right. She suffered intractable pain that did not respond well to drugs and was offered a 'nerve block' as an alternative therapy, but it was explained that the severe pain in her leg might be replaced by loss of feeling and movement. In this situation a temporary block is frequently undertaken so that the patient may control the eventual choice:

'I want to be able to walk once more but the pain has gone. Better to be without the pain'.

Being able to choose was particularly important when it came to food; to have food that is acceptable is generally important to people, ill or
well, and even more so when symptoms such as nausea, vomiting and anorexia exist. Here the patient was likely to know best what could be managed. Some food that was popular with many people could appear particularly inappropriate to others:

Mrs N (Hospice), 'The food - sausage roll and baked beans - I am sitting here with the bowl in my hand wanting to be sick'.

In this situation it was important to be able to have food cooked as you liked and alternatives made possible, even as sometimes happened it meant someone going out specially to buy it. However, Mrs N could not suggest anything that she would like.

Mrs A (Hospice), 'If I wanted for breakfast - I am a bit of a fusspot - whatever is your fancy you can have it - like eggs boiled 2½ to 3 minutes - at the other (hospital) we could have had a game of football with them. Any of the ladies who want anything special can have it - you could have a drink - alcohol brought in'.

When appetite was fickle it was worrying:

Mr T (Hospice), 'The food position - sometimes I can manage and sometimes not - it worries me'.

Therefore it was important to be able to respond to appetite without too much comment by staff:
Mrs PN (Hospital), 'Food, you could have it or leave it'.

Mr B (Hospice), 'If I eat - no comment - if I don't eat - no comment'.

Such lack of comment by staff gave the patient control over whether they ate or not; it was important to quality of life to give up the struggle when desired.

It was also important to have food presented well. For Mrs PH (Hospital) this had not been the case:

'The food ... half cooked sometimes ... yesterday had poached egg - no salt - laid in a plate with couple of spoons of water'.

The way the whole meal was presented was important, comments to this effect were made by women. Mrs V (Hospice), 'Nothing is too much trouble - trays are laid so nicely'.

For Mrs GD (Hospice) expressed the various considerations that needed to be made with regard to food in terms of variety, quantity, quality, and manner of presentation. For her these were right:

'I am very well cared for - have no personal worries about food. I don't have to think about what to have - it arrives beautifully served and hot - and in the right proportion. I like the arrangement of having a main meal during the day and a little meal on a tea-plate
in the evening - you are not overburdened it's very important - a tiny meal - nicely served plus a little bit of milk pudding if you want it - all very well balanced.

Partnership between staff and patient was important in many areas of care and particularly that of food. Food symbolised opportunity for control as well as for nutrition, it was important that it was acceptable to patients and presented well. These findings are consistent with those of others who have investigated food presentation for the terminally ill (Willans, 1980; Charles-Edwards, 1983; Williams and Copp, 1990)

CONCLUSIONS
In this section physical comfort in terms of effective symptom control and good nursing care has been seen to be a factor of vital and basic importance to the quality of life of respondents; for without this comfort it was not possible to engage in wider living. This affirms the placing of physical comfort at the bottom of the Maslow hierarchy (Maslow, 1970). Chapter 6 has noted some very anguished responses to physical distress and intense relief and dramatic enhancement of quality of life when it was relieved.

Organisation, Expertise, Interaction?
The organisation of care, expertise and interactions in care have all had a part to play in achieving comfort for the patient. Good symptom control has been associated with the ability of professionals to apply principles that have been worked out for the relief of physical distress; and failure with the neglect of these principles - thus expertise is
essential. The organisation of care, education of professionals, and availability of those who may be consulted has a relevance for the degree of expertise that it may be possible to offer to patients. These findings highlight the importance of the current drive (Chapter 3) to provide specialist advice in home and community.

However, staff will not be able to maximise their skills if they do not have the necessary time. There was an indication that nursing skills were at risk when staff came under intense pressure of work, particularly in the acute ward when basic nursing skills may have to compete in priority with other skills needed to support medical and surgical interventions. And yet, the meticulous attention to basic nursing techniques was so vital in contributing towards the comfort upon which quality of life depended. Drugs might be essential but they could not take the place of this kind of expertise.

References were made in the hospital venue to considerable pressure of work in busy acute wards, but not to any specific neglect. Four hospice patients made similar but stronger references to their past hospital experiences. Although the hospice could be rushed at times, the overall impression gained was that it was able to give more time to patients, since there was less diversity of demand upon staff there, and staffing levels were also relatively high. However the suggestion was also made that skilled nurses were being inappropriately used in the hospital; nurses were having to carry out some tasks, that were not seen as essential to nursing, at least to the patient. This is a situation that
has been encountered in nursing over the years and is further discussed in chapter 18.

The quality of interaction between professionals - efficient interdisciplinary teamwork - has also been important, as well as efficient communication between professionals of the same discipline. Specialist advice was available around the hospice yet it clearly was not consulted for patients to be admitted in such distress. This may in part be failures in communication, but there must also be the willingness to recognise that more help is needed, and to seek this as soon as problems arise. Quality of interaction between professional and patient has been important to the building up of relationships most conducive to encouraging partnership necessary to effective care; here personal characteristics of professionals inspire or inhibit the patient's trust and communication.

Organisation - management, expertise and interaction - are all important therefore and must all relate and unite in aim, if the patient is to experience the most basic and vital quality of life factor; that of physical comfort. For without this nothing else may seem to matter - there is no quality of life.
SECTION V

QUALITY OF LIFE AND HAVING EMOTIONAL COMFORT
'Distress in terminal malignancy may be divided into two broad categories - physical and emotional'. (Cassidy. 1986:717)

It was not surprising that at interview a large majority of respondents, 42 (81%) of the hospice 'random' sample and 19 (86%) of the hospital sample spoke in some way of their emotional response to the illness situation. There were many emotional concerns associated with serious illness and institutional care that impinged on quality of life: the emotional response to the disease and especially to the prognosis; living in a ward with very limited privacy; watching others suffer; the boredom and loss of control associated with institutional routines. The key concepts here were fear, and despair, and a range of other negative feelings including anger and boredom. These all diminished quality of life.

In contrast to these were concepts that brought emotional comfort and enhanced quality of life - these centred around hoping and coping in the stressful situation, and drew their grounds from the personal resources of the individual, from interactions with others, and from various elements within the care situation.

This chapter, the first of four in this section, looks at the comments of terminally ill patients on the emotional distress that reduced their quality of life; chapter 9 explores the effort to reduce this distress.
and enhance quality of life by hoping and coping. The second half of
this section is concerned with emotional comfort in the provision of
care; chapter 10 is concerned with the relationship between being able
to hope and cope and receiving news of a bad prognosis, and how this
effected the patient's quality of life; chapter 11 focuses on the
comforts that relieved emotional distress in the care situation, thereby
enhancing quality of life.

The definitions of the concepts particularly appropriate to this section
are all taken from Chambers (1973):

**Distress** is defined as 'extreme pain or suffering' (P. 377) - the focus
in this section is on that which is of an emotional nature, it was often
considerable in extent.

**Stress** is defined as 'hardship, strain, pressure, force' (P. 1336). In
this project stress is related to the emotional hardship and strain of
being fatally ill, and to the pressures and strains that arise out of
the care situation - receiving care and sharing care.

**Fear** has been defined as 'a painful emotion excited by danger;
apprehension of danger or pain' (P. 478). It is thus based upon real or
imagined grounds for belief in something bad, or a threat to something
that is valued, the loss of which would be painful.

**Anxiety** is associated with fear in that it is a state of 'being uneasy
with fear' (P. 56).
Hope is defined as 'to cherish a desire of good with some expectation of fulfilment' (P. 628). To hope therefore requires grounds for hoping.

Despair In complete contrast to 'hope', despair is defined as 'to be without hope' (P. 349), thus having no apparent grounds for hope.

Cope To cope is defined as 'to contend, to deal (with) successfully, to encounter, meet' (P. 286). It therefore involves confrontation with problematic situations and some mechanism for dealing with them. Many of the mechanisms described by patients related to finding grounds for hope of various kinds.

Comfort is defined as 'to strengthen, relieve from pain or distress, soothe, cheer...; whatever gives ease, enjoyment, provide freedom from annoyance' (P. 260). Comfort is therefore related to emotional as well as physical distress, and all of these definitions have a relevance to this study. Comfort has been described in the broad sense as the minimising of psychobiologic stress (American Nurses Association, 1979). In this section it is emotional comfort that is considered and its relationship to the quality of life of the patient.

BACKGROUND - DYING AND LOSS OF EMOTIONAL COMFORT
Maslow (1970) states that once physiological needs are well gratified then the safety needs emerge, that is, those needs that are associated with security, stability, dependency, protection, and freedom from fear, anxiety and chaos. It is just these needs that are deprived when an individual is faced with an incurable and life threatening illness. The
stability of life, its structure, roles and dependable routines are subject to change, and the likelihood of death in a foreseeable future has emerged as a distinct and frightening possibility; the many hopes for life are replaced by a multitude of fears.

Parkes (1978) outlines the response to such situations, the defence against threat, and the painful attempt to adjust to new realities in order to regain emotional equilibrium in finding new bases for hope. Here fear and hope fluctuate and mingle:

"Two main components have been identified as regular occurrences whenever a person is faced with the need to abandon one set of assumptions about the world and develop another. On the one hand there is fear, apprehension, and attempts to ward off the dangers which may yet be averted; on the other hand there is grief, mourning and a tendency to move towards the realization of the new situation which is emerging". (P. 44).

The universality of these occurrences is evidence of man's deep need to maintain emotional comfort. If the individual is to ward off danger and not be overwhelmed by painful emotion, then defence and coping mechanisms must come into play; and if he is to restructure his world in the light of what is happening then he must pass through a gradual, and often painful, process of adjustment. A range of powerful and mixed emotions are associated with the dying trajectory which in their painfulness are not associated with good quality of life; fear and anxiety, depression, guilt, anger, despair (Kubler-Ross, 1970). There
may also be hopes of various kinds and peaceful acceptance. The patient will often swing backwards and forwards between negative and positive emotions experiencing fear, despair, and hope in relation to the many different dimensions of life.

Painful Emotions

Cancer patients are no strangers to fear and anxiety right from the early stages of the disease. As Morris (1986:27) states, 'the fear of cancer is the fear of pain'. Confrontation with a diagnosis of cancer is also confrontation with the possibility of death, a shortened life with potential for suffering in that life (Milton, 1973; Young and Longman, 1983). After the initial onset of the disease a patient may experience several episodes of the return of symptoms followed by treatment and remission. It is likely therefore that there may be peaks of fear and other painful feelings.

Intense anger has been noted throughout the stages of illness, when diagnosis is first made (Peck, 1971), and when the patient is dying (Stedeford, 1984; Parkes, 1984; Bloch, 1980; Kubler-Ross, 1981). There may be anger at being issued with such a fate, anger towards doctors who have been inefficient or who have 'failed' the public expectation of them as healers. Anger may be directed towards family members who do not seem to empathise. Feelings of anguish and helplessness may also be displaced on to others in the form of anger. Kubler-Ross (1970) sees anger and other painful feelings as part of the process of working through to acceptance of the situation.
Different levels of anxiety and depression have been found in research with cancer patients; who have been compared with groups of patients suffering from other diseases. No very clear picture emerges when research is compared for there are many variables involved including, the form of cancer, the stage of disease, the research venue, and the research method used. Koenig (1967) compared a group of patients with cancer of the intestine, with a group suffering tuberculosis, and another group hospitalized for depression; although about a quarter of the cancer patients were significantly depressed, this was less than the depression identified in the other groups. Plumb and Holland (1977) found in 97 patients with advanced cancer of varying types that only 23% exhibited depression.

However, considerable anxiety has been identified amongst cancer patients; Bronner-Huszar (1971) in an early study found that cancer not only interfered with daily life but was associated with anxiety, loss of self-esteem and a disruption of defence mechanisms. Roberts (1972) interviewed 112 women with breast cancer and found that 50% were anxious or depressed. Craig (1974) found that over 30% of patients with leukaemia and lymphoma were anxious. The highest level of anxiety was found amongst 50 cancer patients, with different sites involved, who were undergoing radiotherapy treatment; of these, 98% were rated as anxious and 75% as depressed (Peck and Boland, 1976). It would appear that anxiety and depression are often associated with cancer but there cannot be the automatic assumption that this will be the case (Worden and Weisman, 1977).
The patient who has reached the terminal phase of the disease may well have undergone a series of frightening episodes and is now faced with death. His sense of helplessness is heightened when the result of long struggle is still failure. Kubler-Ross (1981:20) defines the fear of death as 'the fear of a catastrophic destructive force bearing down upon me, and I can't do a thing about it'. This broad definition focuses on the terror of helplessness in the face of an approaching, and frightening unknown; and encompasses both the process of dying, and the state of being dead. There is some general agreement that the fear of the former predominates in the mind of the patient (Bloch, 1980; Cassidy, 1986; Witzel, 1975).

The Fears of Death and Dying

Many researchers have noted the fears of death and dying and analysed them within a variety of conceptual frameworks. For example, Wass (1979) postulates four categories of fear: the fear of dying; of death; of the social consequences of death; and of the dying of others. These categories include global fears such as fear of the unknown, of which the state of being dead is a part, as well as those that are specific. When those around the patient infect him or her with their own fear about the situation then this has been termed 'reflected fear' (Parkes, 1973; Mount, 1978).

Parkes (1973) noted the specific fears of 61 hospice patients referred for psychological support; the most common was the fear of separation from loved people, homes and jobs - 38%, followed by fear of dependency and loss of control - 23%. Fear of what would become of the family was
expressed by 20%, and fear of failure to complete some life task by 10%.
A miscellaneous group of other fears was expressed by 7%; these included
fear of pain, illness, mutilation, of death as punishment, and reflected
fear. These categories therefore represent fear of deprivation in all
the Maslow categories of need; of physical comfort, security, love and
belonging, self-esteem and purpose or self-fulfilment. In view of the
widespread fear of physical suffering, the proportion of those fearing
such distress was surprisingly low. However, the results may reflect the
characteristics of the research venue, an institution well known for its
expertise in symptom control.

Fear of physical suffering includes fear of the pain of the progressing
cancer, of treatments, other symptoms, and complications such as
bedsores (e.g. Bloch, 1980; Mount, 1978; Kubler-Ross, 1981). Witzel
(1975) noted that more fear was associated with dyspnoea or shortage of
breath than with other symptoms. Another fear that has been noted is
that of being defined as dead before being actually dead (Zorza, 1980).
Other fears relate to social loss, for as discussed in Section VI, the
process of dying slowly inevitably brings a loosening of some of the
ties that bind people together; there is the loss of shared roles, and
interests, and with these losses in identity. Care and treatment may
require removal from home and all that is familiar; there are realistic
grounds for separation fears and the fear of loneliness and possible
abandonment if the patient becomes too much of a burden; and this fear
extends to abandonment by professionals (Bloch, 1980). In addition, love
and belonging fears include fear for the future of loved ones,

In addition to these fears there is the fear of loss of self-actualisation, that is the fear that is associated with potential losses of achievement; goals that cannot now be attained, projects and plans which may be hindered or never realised. It is also the fear that hobbies and interests that make life meaningful will go, or that the life that has been lived has had insufficient meaning and the opportunity has now gone to do anything about it (Krant, 1974; Mount, 1978; Wass, 1979).

A different category of fears are those that are associated with death. Choron (1963:107) stated, 'the human mind is as little capable to contemplate death for any length of time as the human eye is able to look at the sun'. This response is recognised as a protective defence, a bulwark against constant anxiety and fear (Wass, 1979). The fear associated with death has several facets, one being that of life after death. Whether an individual has an active religious belief or not, there is so much in religious tradition, its music and its art, to ensure that thoughts of life after death are deep in human consciousness. Christian teaching, and that of other religions such as Buddhism, link the quality of an after life with the one that has been lived. The fears of life after death therefore centre around beliefs in future punishment, and being unprepared to face some form of judgement.
The fear of being dead, of being nothing, is a different and unique type of fear; for normally fears are based upon some form of anticipated painful experience, but this is the fear of not feeling or experiencing. This focus on the absence of experience relates to the loss of identity, it is annihilation fear (Weisman, 1972). In his monograph, a critical evaluation of Heidegger's stance on death, Edwards (1979) describes this type of fear or anxiety:

'Deadness, however, is not a painful experience. It is not an experience at all. When I am dead, I will not be in pain, I will not be ill, I will not be rejected, unfairly criticised or in any other way mistreated. However, even after I have fully realised this, the prospect of deadness continues to be horrifying and at times quite unbearable ... it is difficult to bear the thought that after I have died, I will be unable for all eternity to do any of the things that made life interesting and enjoyable and, what is equally unfortunate, to do any of the things I would have liked to do but never did ... it is this totality which most people find so unbearable'. (P. 58)

In as much as people are unable to think about this concept or listen to feelings about it, and it has been found that doctors are often unable to do so (Twycrossa, 1975a), then the dying must suffer in isolation.

Factors Influencing the Potential to Fear

The question arises as to whether some groups of people are more afraid of death and dying than others. Research suggests that the sex of the
individual does not play a part but that age does; the young have more fear (Witzel, 1975; Kalish, 1981). This may be partly because the elderly have already lived a life which may not have been easy; they have less to lose than the young. Weisman and Hackett (1961) reported a small group of patients who looked forward to death. They were not in the main characterised by being depressed but by a belief that death, oblivion or otherwise, had more to offer than life. There is evidence that fear diminishes as death draws closer (Feigenberg, 1980). Witzel (1975) compared a group of dying patients with others who were seriously ill. Only 2.7% of the dying were afraid, over half of whom expected to die, compared with the 47.9% of the seriously ill who were afraid. It would appear that fear may diminish as death approaches.

Personality factors may also play a part. Miller (1983) studied the coping strategies of 56 chronically ill patients, 12 of whom had cancer. Some tended to face their situation and were called 'approachers'; they were more anxious than 'avoiders' who minimised their situation or repressed their feelings. Whilst it is difficult to elicit levels of fear from respondents who may be strongly denying their situation, these findings agree with Zuelhke (1975) who used psychological measures to assess changes in a small group of dying patients before and after psychotherapy. After treatment there was an increased willingness to face reality, accompanied by greater awareness and admission of fear.

As has been noted, specific fears can be associated with religious beliefs. Witzel (1975) noted that those who had firm belief, and those who had none at all suffered the least fear. This would appear to be a
logical outcome for religious faith is often associated with the hope of Divine support and comfort in this life and good in a future one. Thus such faith is a defence against fear and a means of coping (Miller, 1983). For those with no belief of this nature they would at least be unlikely to harbour thoughts of future ill, whilst those who were uncertain, fluctuating, or felt their faith had been neglected in life would not share the advantages of either end of this spectrum.

RESEARCH DATA - PAINFUL EMOTIONS
As might be expected the illness situation was the major issue at interview for respondents. Forty-two (81%) of the hospice 'random' sample and 19 (86%) of the hospital sample talked of some aspect of their emotional response to it, and to their quality of life. Emotional distress diminished quality of life and its relief brought emotional comfort which enhanced it. This similar high level of statements relating to the emotions in both venues, indicates the importance of emotional comfort to quality of life as well as the need to talk about the emotions.

Many people who spoke about their illness named it openly, without shrinking from the term ‘cancer’. Mrs H (Hospice) was one, she just said, 'I have got cancer'.

Mr I (Hospice) preferred not to use the term ‘cancer’ saying ‘I have big C, emphysema and stones in my kidney’. He was one of the
most fearful of the patients - perhaps 'Big C' sounded less threatening.

The type of emotional distress that was expressed included anxiety and fear, sadness, shock, anger and despair. These related to the patient's awareness of the seriousness of the illness; for this awareness influenced the understanding of what there was to be frightened or despairing about.

Patients' Expressed Awareness of their Health Situation

Patients expressed different states of awareness of their health situation; Table 8.1 indicates the tenor of this awareness at the first interview:

<table>
<thead>
<tr>
<th></th>
<th>Hospice 'random'</th>
<th>Hospital</th>
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<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Improved health</td>
<td>10</td>
<td>19</td>
</tr>
<tr>
<td>Chronic ill health</td>
<td>11</td>
<td>21</td>
</tr>
<tr>
<td>Dying</td>
<td>16</td>
<td>31</td>
</tr>
<tr>
<td>Future uncertain</td>
<td>10</td>
<td>19</td>
</tr>
<tr>
<td>No clear statement</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td>52</td>
<td>100</td>
</tr>
</tbody>
</table>

Expectations of Improved Health It was not surprising that those patients who focused on 'getting better' did not talk extensively about
fear and anxiety. Statements categorised as 'improved health' centred on expectations of some improvement whether small or large. They ranged from complete recovery, for example:

Mr L (Hospice), 'Getting better ... going home ... going back to work', (First response),

to lesser approaches towards normality. For example:

Mrs PE (Hospital), 'Getting better, going home and trying to do what I used to before - seeing grandchildren and doing bits and pieces'. (First response).

The background to these hope statements is discussed in chapter 9.

It is noted in table 8.1 that over twice the proportion of patients in the hospital expressed hopes of getting better than in the hospice; this is not surprising since the hospital patients were in a curative setting and most had been admitted for some form of treatment or investigation, moreover, as is discussed in chapter 10 it appeared that it was not always easy in the hospital to obtain accurate information as to prognosis. It was at first more surprising that 19% of hospice patients should have expressed these hopes. However, although St Joseph's is very well known for its care of the dying it also has a wing for the care of chronically sick people and one for rehabilitation; a patient admitted there would therefore not automatically think it was for terminal care.
Expectations of Chronic Ill Health

Expectations of chronically reduced health came from 21% of the hospice sample and 13% of the hospital; these were the people who did not express expectations of improvement or of imminent decline, but expected to continue to need care because they could no longer manage. For some this was associated with age. For example Miss D (Hospice) said,

'It is really beautiful in here. I could never believe there was such a beautiful place for elderly people to be cared for'.

Expectations of Dying

Others, 31% in the hospice and 23% in the hospital, talked more directly of approaching death although it was usual to use some other term than dying. For example:

Mrs A (Hospice), 'My time is numbered'.

Mrs B (Hospice), 'I'm here for terminal illness - I have cancer - meanwhile I have settled'. (First response)

Mrs G (Hospice), 'I never realised what was going on with me until too late - I went right down to nine stone'.

Sometimes the reference to dying was indirect. For example, Mrs V (Hospice) first spoke of others who had died and then gently led into her own situation. She quoted the surgeon as saying to her, 'You realise that this has gone a bit far'.
One of the most oblique references to dying came from Mrs D (Hospice). She first spoke of the death of a patient in the ward and then talked of taping the Bible story of the raising of Lazarus from the dead, for some children the previous year; at a time when she was already very ill. She said of this, 'The words came slowly'. Later she talked of taking some children to an art exhibition where there were four pictures, the first two contained a figure of a man, the last two were blank. When asked about this the children said, 'He is gone'. She said of this, 'How well children understand these things'.

**Gender Differences** In both venues a greater proportion of women than men were more aware, or more willing to express the understanding that they might not, or would not improve in health. In the hospice 36% of men compared with 7% of women spoke of hope for improved health; 90% of women compared with 46% of men expressed uncertainty or awareness of decline. In the hospital this was not so marked but the trend remained the same: 43% of men compared with 40% of women spoke of hope for improved health and 60% of women compared with 57% of men expressed uncertainty or awareness of decline. This will be discussed later at the end of this section and in chapter 18.

**PAINFUL EMOTIONS AND DIMINISHED QUALITY OF LIFE**

It became apparent very early on in the research that as respondents considered their disease they experienced a range of emotions that were quality of life reducing in their painfulness. These included anxiety and fear, grief, anger, shock and despair. Sixty-nine percent of
hospice patients and 55% of hospital patients spoke spontaneously of some painful emotion (Table 8.2); that this should happen within a few minutes of introduction to a stranger is evidence of the strength of feeling and the need to share it.

Table 8.2 Types of emotional distress associated with the disease spontaneously expressed by hospice 'random' sample and hospital sample

<table>
<thead>
<tr>
<th></th>
<th>Hospice (n = 52)</th>
<th>Hospital (n = 22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety and fear</td>
<td>27 52</td>
<td>7 32</td>
</tr>
<tr>
<td>Sadness</td>
<td>18 35</td>
<td>5 23</td>
</tr>
<tr>
<td>Shock</td>
<td>6 11</td>
<td>- -</td>
</tr>
<tr>
<td>Tension</td>
<td>5 10</td>
<td>3 14</td>
</tr>
<tr>
<td>Anger</td>
<td>3 6</td>
<td>2 9</td>
</tr>
<tr>
<td>Despair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None expressed</td>
<td>16 31</td>
<td>10 45</td>
</tr>
</tbody>
</table>

* Percentages do not sum to 100%, some patients expressed more than one type of distress.

Since no specific questions were asked Table 8.2 reflects the minimum of painful feelings experienced; those distresses that respondents spontaneously chose to express. Most types of distress were expressed by a greater proportion of hospice patients. It is difficult to make comment on this when the basis of the statistics is spontaneous expression. It may have been that some hospice patients were more open to discuss feelings in an institution that particularly encouraged them to do so. As noted in Table 8.1 a greater proportion of hospice patients expressed awareness that they would not improve in health and therefore this greater awareness may account for some difference. These statistics may also reflect a situation in the hospice in which, being continually
surrounded by the death and dying of others, it was very difficult to escape thoughts of loss and death.

Anxiety and Fear

The anxiety and fear expressed by hospice and hospital respondents was categorised into four broad types (Table 8.3).

<table>
<thead>
<tr>
<th>Types of fear</th>
<th>Hospice</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>The fear of uncertainty</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Fears of deterioration/dying</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Fear for the family</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Fear about home/social arrangement</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>No fears expressed</td>
<td>27</td>
<td>8</td>
</tr>
</tbody>
</table>

* Percentages do not sum to 100%, some patients expressed more than one type of fear.

The Fear of Uncertainty

The fear of uncertainty expressed by 13% of the hospice 'random' sample and 9% of the hospital sample was often very intense; it is difficult to draw upon emotional defence mechanisms when the 'enemy' is unknown. Mr I (Hospice) described his situation:

'They found a cyst on my liver - you know what that means straight away - it is not a gum boil. They tried another operation - was a failure. They tried to kill the cyst - sent me back home - had a conference - decided to open me up and found a cyst on my liver. They think they have now blocked it off - it depends whether they have got it in time before it goes anywhere else - it has come from somewhere else. They say (previous hospital) I have a 50/50 chance. It is horrible to think about it but there is nothing that you can do about it - you have to take your fate'.
Mrs PC (Hospital), 'The waiting is the worst part'.

The Fears of Dying Fears of dying were expressed by approximately a quarter of each sample. Sometimes this was in general terms. For example:

Mrs D (Hospice) 'Fear, fear, fear in plenty'.

Miss LD (Hospice) 'Everything about death is so black - if they could only change it to navy blue or grey'.

Women appeared to be more open in their expression of fear; men more often expressed fear indirectly indicating that it was being repressed; there was an intensity in their statements. For example, for Mr G (Hospice) fear was expressed as the fear of talking about dying. When he was first approached and asked if he wished to partake in the research he exhibited intense fear and said, 'You have come to talk to me about dying haven't you'. When assured that the subject was quality of life and that he had no obligation to take part he relaxed and said he did wish to comment, and then said, 'Thought it was about dying - I have cancer and secondaries in my spine - am not going to get better'. His fear of the situation was such that he could only approach it indirectly, and when he was able to lead the way.
For Mr S (Hospice) his fear surfaced indirectly in a dream; there was an intensity in the way he made this comment:

'If it wasn't for my waterworks I would be on top of the world - whether its hallucination or not I woke up feeling as a dead person just now - strange - shocking'.

Mr C (Hospice) also explored fear indirectly, in relation to the death of others. He was afraid of his comments being written down as if the act of doing so would confirm them:

'In here today - not too happy - I think to myself that there has been a death - not nice - disturbing'.

The fear of dying had many components, one was of physical symptoms such as paralysis, constipation, choking. For Mrs T (Hospice) it was pain:

'I know what I have got and am not afraid - the only thing is will the pain get bad?'

For four patients with a brain tumour it was mental deterioration that they particularly feared, with its potential for loss of dignity. For example, Mrs J (Hospice):

'I have a brain tumour - tell my daughter that if I become funny they can put me in one of those places - I don't want to be shown up - yes I am afraid - maybe it won't happen for some time but I am'.
Fear for the Family  Approximately 15% of each sample expressed fear for the family. Four patients between the samples had relatives handicapped from an early age. For example:

Mrs F (Hospice) said, 'I have a handicapped daughter and am concerned'.

Mrs FD (Hospice) was in her 40s. She said,

'I am not settled - cannot settle - have a handicapped son - think of him all the time - aged 16 - he is not physically handicapped but mentally ...In a year or two he would have been able to manage on his own - I think of him all the time'.

Mrs N (Hospice) needed to sell her business in order that her family could be helped. She spoke of this through three interviews:

'I have a business and how will my daughter sell it without me'. (First interview).

'If this could be done I would be as happy as a queen. The problem is I don't know how long I have got to see it through'. (Second interview).

'Wanted to get rid of that property of mine'. (Third interview).
Another form of deep anxiety centred around the effect that the illness was having on the family; for three patients their families were already under different forms of strain, and two were concerned about the extra burden of visiting, especially when long journeys were involved. The other, Mr A (Hospice) said:

'I have one big worry - my son was an alcoholic and came off drink helped by the Salvation Army. Alcoholism placed a great strain on his marriage - now he has reverted to drink with the shock of the (my) illness'.

Fears about Home and Social Arrangements. Four women in the hospice expressed fears about their home and financial arrangements - none appeared to have close relatives who could help.

Mrs I (Hospice) said, 'When one comes into hospital one starts to worry about things at home ... you are not there any more'.

Miss C (Hospice), 'I am worried about my rent, my pension, my home'.

Miss B (Hospice) was concerned that she had not informed Social Security that she was resident in an institution and could be blamed for continuing to receive extra pension. She said,

'That is the sort of thing that worries me - I have not notified them - he (the Social Security Officer) is going to ask the Social
Worker - hospice is a hospital - you get worried in your dealings with the Government’.

These comments on fear demonstrate that for these patients fear was related to every aspect of life - there was fear of physical suffering, social fears related to the family and to financial and other arrangements, fear for loss of esteem, and generalised fear of dying - fear was global because the impact of the disease was global.

Sadness
In many interviews there was an intense sense of sadness - expressed verbally and non-verbally through tone, facial expression, and sometimes tears. This was the second largest group of responses to the situation; sadness was expressed by 35% of hospice and 23% of hospital patients. There was sadness for the loss of health and sometimes regret for not having appreciated it enough when it had been present. For example:

Mrs PI (Hospital) said, ‘You are not aware of your body until it goes wrong - like electricity ... all the time that things are laid on a plate for you - you don’t appreciate - take for granted’. (First response).

The loss seemed all the greater for those who might have expected a longer life:

Mr PF (Hospital), ‘I am not that old, am only 48.’ (Tears)
There was a mourning for loss of opportunity and the natural things of life:

Mrs F (Hospice), 'There never will be time now to do everything'.

Mr U (Hospice) mourned the loss of participation in life:

'They reckoned they could do no more for me - I would love to be able to walk round the park - look at the flowers, the buds, the young kids playing'.

At the end of the interview I asked as usual if I could do anything to help - like make him comfortable - the reply came with great sadness, 'If you could make me better - help me to walk again'. His quality of life assessment was an expression of his sense of loss.

FEELINGS ABOUT QUALITY OF LIFE AT PRESENT

Delighted______________________________________________Terrible

Mourning was not only a case of coming to terms with some overall situation; it occurred again and again with the on-going process of deterioration and each associated loss of ability and opportunity. As will be discussed in chapter 14, men particularly mourned the loss of physical prowess. Around the time of her fourth interview Mrs D (Hospice) had lost control of her bladder and needed a catheter - for her this was a potent symbol of loss and she was very distressed.
There was sadness and depression when hope waxed and waned.

Mr PG (Hospital):

'When you are under treatment you may be a bit depressed with the different treatments you are getting - and sometimes it is not doing what it should do - it takes a while before it starts to work'.

Sadness, grief and depression could take over the thoughts of the patient so that little else mattered at the time. This situation demonstrated the relevance of the Maslow hierarchy (1970). Both of the following patients were physically comfortable but they were pre-occupied with loss; it filled their interviews. Mrs W (Hospice) was mourning her health and lost role of helping the handicapped. She said:

'Really low and bad lots of the time ... I am depressed'. (First response) ... 'It's harder to take than to give'.

She described her sense of loss as, 'like being cut in half'.

Miss A (Hospice), 'Sometimes I feel so sad - maybe for my illness (tears). 'Have you been ill for long ?' 'Two months - I am trying to work it (to get better) but sometimes don't know - all day and night I am thinking about this - I am more sad (tears).
Shock

For others, six (11%) in the hospice and one (5%) in the hospital, emotional distress was expressed in terms of shock and apathy. This was particularly associated with those newly aware of their condition. Some patients could arrive at the hospice hardly having had time to realise that they were severely ill, let alone dying. Mrs Q (Hospice) said:

'You haven't had time to address yourself to a new situation - you can't believe it's happened to you - you know it happens to other people but you feel far from it'.

Mrs HD (Hospice) was in a similar state of shock and lethargy, and yet she wished to share her feelings for when approached about the research she consented but turned her face away. Her words came slowly, with difficulty, and without any expression. She said,

'My problem is that I don't know how I think ... I thought I was coming in for pain control ... seeing the grand-children growing up, and the loss of this ... I had made plans for my husband's retirement. Just to be happy - and watch the grand-children grow up - now this'. (First response).

Mr Q (Hospice) said, 'People keep asking me what I want to do - have only been in here three days - I am here - I don't know what is happening - I need to (understand) - get to the bottom of it - until I can do this I really don't know what is important to me. (First response).
None of these patients knew at the time what mattered to quality of life, apart from their families because, one set of expectations had been shot from under them and they had not had time to generate any others. This was a reminder that awareness of need requires a basis of expectations. Even beginning to adapt to traumatic situations such as these was painful and could not be accomplished rapidly or to order.

Mrs W (Hospice,) 'I have had a hysterectomy, then this happens in my head - but the consultant says it does sometimes - it takes a long time to get used to the idea'.

Mrs PF (Hospital), of the cancer, 'its come back again after all these years - you wouldn't think so. Now I need more care - you have to adjust yourself especially when it first hits you'.

It was possible to experience a state of shock even though the disease had been suffered for some time. When the course has been one of a series of treatments followed by remission it is not easy to realise that the last stage has come. It was not surprising that it was so difficult to settle and partake in the activities that concerned staff tried to provide when the mind was overwhelmed with the situation.

Tension
Six (11%) of patients in the hospice expressed their emotional distress in terms of general tension; this took the form of restlessness, inability to concentrate, feeling overwhelmed and generally flustered.
For example, Mr C (Hospice) who was among the most fearful of the patients said:

'I love reading but I can't settle down' (First interview).
'Towards the evening I get a restless feeling' (Second interview).

Mrs W (Hospice), 'I get flustered - a little thing is a big thing'.

As will be noted in chapter 11 these were amongst the patients who experienced boredom because they could not concentrate.

Anger

The most pronounced feeling accompanying some comments was the sense of anger or felt injustice. Anger was expressed by 10% of hospice patients and 14% of hospital patients; it was directed towards 'life', towards professionals, and towards the family. Mrs G (Hospice) expressed anger at 'life' dealing her such a blow; she associated misfortune with bad behaviour and felt that this did not equate with her deserts. She said,

'I can't see why I should be struck down like this - I can't find anything I have done in my life for this'.

Mrs HD (Hospice) from the hospice convenience sample felt it was unjust that life should be cut short. She said:

'Being only 58 and losing life - it seems unfair'.

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Mrs PG (Hospital) was over 70 but her expectations were based upon what her friends could do. She said:

'You look around and see friends who are practically 100%, who can enjoy life - that's when I find it hard - that's one of the hard things. I find my friends going here and there and enjoying life and I can't do it'.

Two patients in the hospice blamed their doctors for apparently not diagnosing the disease in time, for example Mrs H (Hospice):

'Asian doctor said there was nothing the matter with me - his deputy found it'.

Two other patients felt anger towards relatives who were perceived as being unable to cope with the emotional trauma of the illness. For example, Mrs J (Hospice),

'My husband behaves like a child. He will crack first. I tell him - it is me that has had it not you. It's all the same with alcoholics'.

Despair

Three (6%) of the hospice 'random' sample and two (9%) of the hospital sample spoke of having at some time lost the will to live before their admission. For two women this was because of the difficulties they
had experienced in trying to cope at home. One lived alone, the other had an elderly husband who was also frail. Mrs T (Hospice) said,

'When I was at home I used to say to my husband - I wish I would be dead in the morning'.

For two other women, one in the hospice and one in the hospital, the problem had been social isolation; both were widowed and had lost friends; one still did not wish to live. They are discussed in chapter 13.

The problem for Mr PC (Hospital) was that he felt he was just waiting to die and that his pain which was severe at times could not be properly controlled. He said,

'Knowing what I have got I don't want to live ... that is how I feel'.

Waiting to die with a sense of purposelessness and powerlessness was the basis of hopelessness for Mrs KD (Hospice) who linked the despair of this experience directly with lack of quality of life:

'I don't have any quality of life just sitting here - can't see properly - same old thing day after day - can't do nothing, can't see hardly ... you might as well give up hope take things as they come. I am not a child - will be 87. I've seen some good and bad times'.
As will be discussed in chapter 10, two other patients in the hospice convenience sample found it very difficult to cope with a feeling of 'waiting to die'.

CONCLUSIONS

What is most apparent in the responses is that the situation of coming to terms with dying was a very difficult one, full of emotions destructive to quality of life, and that the same types of emotional distress were experienced in each institution. Emotional distress consisted of fear and anxiety for self and others, of sadness for lost ability and lost years, of anger with life and others who did not come up to expectations, of the shock of recent awareness, and of despair when there seemed to be no answer to problems. A greater proportion of hospice patients expressed anxiety, sadness, shock and tension which was consistent with the findings that twice as many patients there were openly aware at interview of the seriousness of their illness.

As has been noted there were gender differences in that a greater proportion of women in both venues talked of their emotional experiences than men. Men more often expressed fears indirectly, and with an intensity of tone and look that suggested that an attempt had been made to repress feelings. There were also age effects in that one factor that contributed to additional distress was the relative youthfulness in the patient; unlike those who had lived a full life they were faced with unexpected loss of years. There was a difference between the two research venues in the expressed awareness of not 'getting better'; over twice the proportion of patients in the hospice were aware, or willing to express
awareness that this was their situation. These issues will be discussed again at the end of chapter 11, and in chapter 18.

There have been references to issues with which needs theory is concerned, when current hopes and expectations have been suddenly shattered then it is hard to know what matters for awareness of need requires expectations. The intense grief of some dominated the interview, a reminder that a degree of emotional comfort is required before there can be appreciation of higher needs (Maslow, 1970).

In strong contrast to the intensity of some of the statements were the apparently peaceful expressions on the faces of patients in the wards with little indication of underlying trauma. This suggests that emotional distress was there to be released when the opportunity afforded; for people mostly keep face in public places (Lofland, 1972). The findings indicate the nature of a 'below the surface' situation; the very painful quality of life destroying struggle involved in the confrontation with death and dying.
In view of the emotional distress explored in the last chapter, and its negative effect upon quality of life it would be expected that respondents would seek some means of easing discomfort and enhancing quality of life. The means spontaneously offered by thirty-five (67%) of the hospice 'random' sample and sixteen (73%) of the hospital sample was hoping and coping. Hoping statements related to hope of various kinds - getting better - dying peacefully, and to a variety of hope mechanisms. Coping statements related to strategies for coping. This chapter first discusses the concepts of hoping and coping and then explores them in relation to the findings.

HOPING

As was stated in chapter 8 hope is based on expectations for good, however tenuous these may be, and despair is a state when hope does not exist. Hope and despair may relate to any dimension in life, and for life itself. Hope is not easily maintained in the traumatic situation of facing death, when there is no way out. However, hope is an essential part of living (Ainsworth-Smith and Speck, 1982), a vital human value (Erikson, 1975), and a sustaining force that is linked to the will to live (Weisman, 1972). In order to live one has to have something to live for; for when people are deprived of hopes in living they frequently begin a quick downhill course irrespective of their physical condition (Feigenberg, 1980). Dying persons may hold strongly to hope (Raphael, 1983); hope and despair may also fluctuate and can exist simultaneously
with regard to different aspects of living (Feigenberg, 1980). Kubler-Ross (1970) observed that when patients stopped expressing hope then this was often a sign of imminent death.

Hope is therefore necessary to life, and even more so to quality of life; maintenance of some kind of hope in the patient is therefore regarded as a clinical imperative (Kubler-Ross, 1970). It is fortunate that hope may have many dimensions for when one fades another may take its place. In aiming to give dying patients quality of life the aim is to enable them to live with the hope that their needs will be met and that dying will be peaceful. An understanding of hope mechanisms is therefore important to those caring for the dying.

The Dimensions of Hope

Until recently little work has been undertaken into the multi-dimensional nature of hope. Erikson (1975) linked hope to 'expectations of goal fulfilment' but did not elucidate what these goals were. Miller (1984) undertook a qualitative study of the perspectives of hope of 59 persons who had survived severe illness. Ten critical elements of hope were identified; they included the means of hoping as well as the elements upon which hope was centred. Five of the elements related to basic human needs (Maslow, 1970), such as warm social relationships, freedom, purpose in life, and more generally the achieving of goals, and having something to hope for. The remaining elements related to the mechanisms of hoping.

One element essential to hoping was having a sense of the possible. If hope is to be based on secure grounds it requires a realistic perception
of the situation. The perception of the individual is often unrealistic in fatal illness when thoughts of dying are so traumatic that denial mechanisms intervene to protect from the awareness that there are no grounds for hope of recovery (Kubler-Ross, 1970; Weisman, 1972). When one hope cannot be sustained then a lesser hope may take its place to enable hoping to continue. In the dying patient this may take a form of bargaining (Kubler-Ross, 1970), for example hoping for delay in dying. Thus another of Miller's (1984) elements was not imposing rigid grounds upon hope. Alongside the finding of acceptable grounds for hope Miller perceived the search for clues to ascertain whether the grounds were appropriate. Thus when sick persons are talking of getting better they may look into the eyes of professionals searching for some sign of confirmation.

Dufault and Martoccio (1985) collected data through participant observation of 35 elderly persons and 47 terminally ill persons in institutional and home settings; their description of hope contains the element of realism:

'A multidimensional dynamic life force characterised by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant'. (P. 380)

They divided hope into two broad categories; generalised hope, a sense of some future beneficial but indeterminate development, and particularised
hope, concerned with some particular outcome. Generalised hope seemed to derive from an attitude to hoping. They state:

'In some instances, it is as though generalised hope provides the climate for developing particular hopes and later rescues the hoping person when the particular hope no longer seems realistic'. (P. 381)

Dufault and Martoccio further identified six dimensions of hope of any kind, (1) the 'affective' dimension relates to the sensations and emotions that are part of the hoping process, (2) the 'cognitive' dimension to mechanisms of hoping similar to those identified by Miller (1984). (3) the 'behavioural' dimension is associated with the actions taken by persons to achieve hope and (4) the 'affiliative' dimension focuses on the relationships with external 'others' that have an impact on hoping. These 'others' include people, past and present, as well as God (Higher Being or Power, Creative Force). (5) the 'temporal' dimension focuses on time in relation to hoping. Keeping hope non-time specific, for example, could serve as a protective device when the desired outcome seems to be long in coming, and (6) the 'contextual' dimension was important in that it included all the life situations that surround, influence and are part of a persons' hope. Dufault and Martoccio (1985) state therefore that when hope is viewed as multi-dimensional it becomes apparent that some sphere or dimension of hope is always present. This can be one on which those who seek to help patients may try to build.
COPING

The dictionary definition of to cope as 'to contend, to deal (with) successfully, to encounter' (Chambers, 1973:286) has very positive connotations, implying perception of a problem followed by engagement in some activity to deal with it, and hopefully remove it. The dying patient faces a disease problem that is not going to be removed, but rather is likely to increase, thus coping becomes a matter of meeting and minimising the problem of the associated emotional distress. This form of coping is better reflected in Weisman's (1979) definition of coping, as what an individual does about a problem to bring about relief, reward, quiescence and equilibrium. This is conscious coping and different from the protective mechanism of 'denial', the psychological term specifically associated with a subconscious blocking of the awareness of a traumatic event too hard to bear (Weisman, 1972).

Coping Strategies

Cancer patients have been found to adopt a variety of strategies that involve both active and passive approaches to the emotional problem of their disease (Bond, 1978; Miller, 1983). The active approach has been judged, objectively at least, as the most successful (Weisman, 1979), and involves confronting problems, seeking information about them, and taking some constructive action, such as sharing them with others, or accepting the situation and finding something favourable in it. The passive approach is exemplified by behaviours such as suppression of feelings and emotional withdrawal from the situation, or by passive acceptance. However, it is not easy to observe behaviour and neatly categorise it. For example, information seeking may appear to be approaching in nature;
but it may also be avoiding in that the information sought may be subtly selective.

The coping styles of individuals have been viewed as relatively enduring (Lipowski, 1970), but also as capable of change provided the problem is recognised (Falek and Britton, 1974; Weisman, 1979). The latter school of thought sees coping as a dynamic process involving a series of psychosocial transitions based upon cycles of appraisal (Parkes, 1972). Maguire (1980) commented that not enough was known of the context of coping to accurately predict an 'at risk' group of individuals least likely to cope with serious illness; however, certain factors have been identified as likely to help or hinder coping. Plumb and Holland (1977) found that a prior history of poor coping or depression indicated patients who were less likely to cope easily in advancing illness.

Factors Influencing Coping Ability
A variety of physical and psychosocial factors may influence coping ability (Weisman, 1976; Cobliner, 1977; Punch and Mettlin, 1982). For example, the disease process may affect thinking or have particular depressive effects. Some diseases may be more subject to stigma than others, thus isolating the patient. 'Cancer' as an umbrella term encompasses about 100 different illnesses with their different meanings and problems for the patient; the variety of effect can therefore be considerable; and the coping outcome will be further influenced by the patients feelings about, and understanding of, the situation, and his social support (Hinton, 1972). A consistent finding in many studies has been that warm relationships have been important to coping (e.g. Parkes,
1972: Carey, 1975: Weisman, 1979) and this has been born out in clinical practice (Wortman and Dunkel-Schetter, 1979). The variety of variables involved in coping indicate that whilst there are patterns of coping there is also a uniqueness to each individual's situation.

The presence of hoping and coping mechanisms, observed in practice and research; and their widespread use, suggests that it is fundamental to human happiness and satisfaction to be able to meet situations of fear and despair with abilities to hope and to cope. Thus hoping and coping become important to quality of life.

RESEARCH DATA ON HOPING AND COPING BY THE TERMINALLY ILL
Up to this point the concepts of hoping and coping have been discussed separately. In the response of terminally ill patients however, they were often inter-linked, for hoping was a means of coping and to be able to cope was a source of hope. Sixty-seven percent of the hospice 'random' sample and seventy-three percent of the hospital sample talked spontaneously and directly of some form of hoping or coping.

The Need to Hope
Hope ran like a thread throughout much of the response. It could fluctuate and be uncertain, for example Mr I (Hospice), needed to hang on to hope despite his misgivings:

'Dying like me - well perhaps I am not'.
But hoping and coping of some kind was seen as necessary to quality of life. Mrs Q (Hospice):

'You need to hope' - try to cope and hope tomorrow it will be better'.

The main hopes that were expressed were in relation to health prospects. As shown in Table 8.1 around one-fifth of hospice 'random' sample patients and two fifths of hospital patients hoped to improve in health. This hope was often expressed with great intensity. Mr AD (Hospice):

'To get good health again - if I had a chance of a million pounds or good health I would have the health'.

HOPING AND COPING STRATEGIES

To hope strongly for better health was to risk intense distress if hope became lost, and thus alongside hope were presented mechanisms for checking, bolstering, and adjusting the grounds for hope. Contending each day with severe illness also required a variety of coping strategies if hoping and coping abilities were not to be lost. Table 9.1 (over page) shows the types of hoping and coping strategies discussed by respondents. A greater proportion of hospital patients (73%) spoke, about hoping and coping than hospice patients (67%); this difference reflects the greater proportion in the hospital who spoke of hope for getting better. A greater proportion of women than men in both venues spoke of hoping and coping - 77% of women in the hospice compared with 55% of the men, and
80% of women in the hospital compared with 57% of the men. Each of the five types of hoping or coping strategy will be discussed in turn:

Table 9.1 Hope and coping strategies mentioned by hospice ‘random’ and hospital samples

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<th>Hospice (n = 52)</th>
<th>Hospital (n = 22)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%*</td>
</tr>
<tr>
<td>Working with hope</td>
<td>32</td>
<td>62</td>
</tr>
<tr>
<td>Releasing/sharing feelings</td>
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<td>29</td>
</tr>
<tr>
<td>Exercising control</td>
<td>19</td>
<td>37</td>
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<tr>
<td>Approaching situation</td>
<td>14</td>
<td>27</td>
</tr>
<tr>
<td>Avoiding situation</td>
<td>12</td>
<td>23</td>
</tr>
<tr>
<td>No hoping/coping statement</td>
<td>17</td>
<td>33</td>
</tr>
</tbody>
</table>

* Percentages do not sum to 100% - some patients expressed more than one type of hoping or coping strategy.

Working with Hope

Working with hope involved finding grounds for hope, avoiding indicators that there were no grounds for hope, assisting hope, and altering grounds for hope.

1. Finding Grounds for Hope Hope for improved health demanded perceiving some possible grounds for hope, this involved seeking information or exploring the grounds for hope in some way. Exploring statements were expressed by eleven respondents in the hospice ‘random’ sample and eight of the hospital sample. Mrs PH (Hospital) used her past life experience as an indicator and was not encouraged:

'Hope things will work out - have never had much luck in my life - lost mother aged 6 - family scattered - death of daughter (tears) - death of husband - handicapped sister'.
The help of God was the grounds for some. For example, Mrs PJ (Hospital):

'All I want at the moment is to get well (First response) ... to pray all the time because I know what I have got - lets get down to broad facts it is cancer of the gullet - but I am not strong enough yet to operate - but I pray to God that I will get better'.

Others, based their hope upon trust in the staff - Mrs PA (Hospital):

'Knowing they do their best'.

and for some this hope was perceived to be based on good grounds when symptom control began to bring new energies into life, with at least the feeling of getting better. Mr D (Hospice) based his quality of life assessment both on prayer and on his experience of increasing symptom control:

'Hope, always hoping, hoping, hoping - praying - pain comes and goes but beginning to be eased - it is too early to talk too much I think'.
FEELINGS ABOUT QUALITY OF LIFE AT PRESENT

Delighted / Terrible

'Things seem to be going my way and with hope and confidence I feel strong'

When the grounds for hope for life were not good then the possibility of peaceful dying was explored by patients. For example, Mrs D (Hospice) was concerned at her first interview with the last moments of life, and what these had been like for another patient. She said,

'The lady in the bed opposite died a couple of nights ago - I would like to talk to someone about that - Dr. X talked to me about her symptoms and Y said a few words, but it wasn't enough - death is too important to be casual'.

Mrs D observed the dying of others and at her third interview two weeks later had come to her conclusion, saying of another patient who was in her last hours:

'She's peaceful - they can say that here - always when the time comes it is peaceful'
2. Avoiding 'No-hope' Grounds Hope was assisted negatively by avoiding 'no hope' grounds; avoidance of information that might destroy hope was expressed by a small proportion of patients - four (8%) of the hospice 'random' sample and one (5%) of the hospital. For example, Mrs Q (Hospice) said:

‘You sometimes feel the doctors don’t know really - they are hoping you will get better but don’t know - it’s your reaction to treatment that they need’. Would it be better if they said they didn’t know? ‘No, you need hope - and to trust in their judgement’.

Mrs M (Hospice) ‘No news is good news so that is important’.

Two patients in the hospice convenience sample were particularly descriptive. Miss ID (Hospice) illustrated the ambivalence in the wish to know and not to know. She said:

‘The cancer in my mouth is advancing so rapidly I wonder what will be the next stage - they seem to keep pace with the pain - perhaps it is better not to know really. For example, if I thought I might be going to be paralysed I should be waiting for it’.

Miss ID (Hospice) rejected the signs that indicated that the grounds for hoping were inadequate and the opinions of the doctor, and rationalised the symbols of her deterioration:
'I have not written myself off - X here (the doctor) insists that I shall get worse, so I can’t share with X as I can with you. I do not feel within myself as if I am dying'.

Miss ID had some very obvious signs of deterioration - her cancer was breaking through her skin and fungating. She said of this:

'There is an explanation for what is happening - that is the bad coming to the surface'. (coming away).

3. Assisting Hope A small proportion of the patients who spoke about some form of hoping and coping - three (6%) of hospice ‘random’ sample and one (5%) of hospital made statements relating to boosting hope for improved health through personal effort of different types. For Mr PA (Hospital) this meant fighting the disease. For Mr K (Hospice) assisting hope meant being a ‘good’ patient, since his trust was in the staff. He said:

'The most important thing that my wife and myself should get better ... I do whatever they tell me - I am a very good patient - it helps to be able to do this'.

Here the adoption of the passivity of the ‘sick role’ (Parsons, 1951) was commensurate with curative expectations.
For Mrs H (Hospice) who had felt let down by her doctor the struggle to survive would be helped by relinquishing the burden of negative thought:

'Optimistic - you put all the bad sad thoughts behind you and think it might not be so bad'.

Miss ID (Hospice) combined rejection of the negative, as seen above, with hope boosting strategies. Getting better for her meant instituting a complicated regime for herself:

'Finding balance in my whole life, diet is the easiest to control but psychological and spiritual do not actually change'.

4. Altering Grounds for Hope - Adjusting Expectations. When getting better seemed unlikely then emotional adjustment was required if comfort was to be found. This involved finding some kind of fall-back position that could be accepted, or the slow adjusting of expectations to the reality. Adjustment type statements were made by fourteen of the hospice 'random' sample and eight of the hospital sample. Bargaining was the approach used by Mrs H (Hospice):

'Partial health would do but full health would be better - I have got cancer'.

Hoping expectations could be reduced to a bare minimum, to be taken day by day - life in itself was valuable.
Mrs T (Hospice), 'Thank God I have got over another day - it's nice to know you are still here and you have got over another day - we all know what is going to happen in the end - but I don't let it worry me'. (First response).

Miss D (Hospice), 'I've lived one more day because when I came in here I didn't expect to live'. (First response).

The effect of reducing expectations featured directly in Miss D's assessment, it enhanced her quality of life:

FEELINGS ABOUT QUALITY OF LIFE AT PRESENT

Delighted

Terrible.

'Every day is a blessing'.

It was not easy for many patients to accept reduced hopes and expectations, the emphasis was rather on striving to accept to attain peace of mind, for the phrase usually used was 'I have to accept or have got to accept'.

Mrs C (Hospice) 'I know I am sick and have to accept it'. (First response).

Mr O (Hospice) 'I have got to accept the fact that I am suffering from an ailment that is incurable'.
Mrs PG (Hospital) 'My main thing is that I have got to accept - one realises that things happen - you don’t realise that it is going to happen to you'.

The reducing of expectations - the finding of acceptable hope fall-back positions did not come easily, it involved accepting that the original position held was now no longer tenable - Miss LD (Hospice):

'I don’t want to die yet - have come to terms with dying in general but not the time yet'.

The most frequent strategy for assisting reduced expectations and acceptance of the situation was the use of time frameworks. The length of time that she had been ill was one element in acceptance for Miss B (Hospice):

FEELINGS ABOUT QUALITY OF LIFE AT PRESENT
Delighted_____________________________Terrible

'in between'

1. 'The syringe driver has eased pain
2. 'I twigged about my illness - matter of months - knocked me back coming to St Joseph's because I knew what it was for - but I have been ill for a long time'.

Mr I (Hospice) adopted the same approach with regard to his age of 70+ as did others:
'Whose life is so delightful when you get to this age - it is as good as you can expect'.

When death was anticipated it was important to the quality of life of the present to feel that it would be peaceful and dignified. Mrs J (Hospice) who had a brain tumour and was so afraid of mental deterioration expressed this hope as she talked of her mother's peaceful death a few weeks previously. When she was asked for her quality of life assessment she said:

'I would like to go like that'.

However, since hope by definition is related to expectation for good, it could not be reduced (Chambers, 1973:628) beyond this expectation - something good had to be found in the situation. As will be discussed in chapter 15 the response of Mr I (Hospice) to a situation in his past hospital which he saw no hope of good was to remove himself from it as soon as possible and ensure that he never returned there again.

Up until this point the discussion has related to the ways that patients worked with hope, it now turns to various other coping strategies that were noted in Table 9.1 - to releasing and sharing feelings, exercising control, approaching and avoiding the situation.

Releasing Feelings
The sharing of feelings was the means of coping with the situation, voiced by fifteen (29%) of the hospice 'random' sample and three (14%) of
the hospital sample. In addition many others demonstrated by the way that they wished to share their feelings in the research that this was their approach. Emotions were shared with the family, with nurses, with those offering pastoral care, with other patients. For example, Mrs J (Hospice) said:

'I have a daughter I can talk to'.

Mrs E (Hospice) 'I endeavour to share - it helps'.

The support of family and friends, of staff and other patients is explored in chapter 12.

The research was also overtly used as a means of off-loading feelings. For example, Mrs D (Hospice) was feeling upset about her situation. She needed to talk to someone 'outside' of the ward situation. Her fourth interview began with:

'Thank goodness you have come'.

Mrs MD (Hospice) was upset over the death of another patient and worried about her own condition. She expressed her feelings a little and then cried and asked me to come back - this happened again and was followed by another request:

'Please come back and talk - I have appreciated it'.

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Of these patients who spoke of releasing feelings three (6%) of the hospice ‘random’ sample patients spoke of the importance of venting feelings through crying or anger. Two women spoke directly of the benefit of being able to cry. Mrs O (Hospice) said:

'To have a good cry and then after that I feel better'

Mrs A (Hospice) ‘Sometimes you want to burst forth’

It was suggested by the ward staff that Mr PA (Hospital) should be invited to partake in the research not only because he fitted the criterion of being terminally ill but because he was ‘a bit low’. He immediately talked of his condition which he felt was serious and said:

'To let off steam - feel better for it ... come again’ (tears).

Mrs D (Hospice) would have preferred to express her feelings through anger but felt inhibited by the reactions of some of the staff who sought to placate her by reasoning with her; it was easier then to resort to tears. She was angry about her physical weakness which forced her to wait until others could help her. For her, anger seemed less demeaning:

'Anger - no frustration really because for example the commode (by the bed) is four inches away from me ... I would like to say if you don’t want to do it I will do it for myself but I daren’t in case I fall ... I say things (when they try to reason) like "How dare you - you have no right to say that" and then the tears come - it helps in
so far that they leave me alone when they see me crying - they don’t
go on with their remarks - they shut the door on it‘.

Exercising Control

A major way of coping with the illness situation was to seek to maintain
personal involvement in all living activities in terms of choice and
control. Most statements expressed a determination to retain as much
independence and choice as possible rather than to manage the total
situation or dominate others. Choice and control statements feature in
some detail throughout the findings and may be found in every section of
this thesis. Choice and control was appreciated in both institutions, and
control statements were expressed by nineteen (37%) of the hospice
‘random’ sample and seven (32%) of the hospital. For example:

Mrs X (Hospice) ‘I am always happy because the nurses do as you want
them to do’.

Mrs PF (Hospital) ‘The nurses - always helpful - will do anything
for you’.

Mrs E (Hospice) ‘You can give your own instructions’.

It was of interest to seek to identify the characteristics of those
respondents who spoke of control, whether this control was related to
physical comfort or any other quality of life factor. They came from
patients who were relatively fit in terms of symptom control and energy,
and almost entirely from those who were aware of the seriousness of their
condition, only two from each sample being focused on 'getting better'. Whatever the reason, the impression is gained of a group of patients, who having their comfort needs met, expected to use their remaining days as much as possible in the way that they felt best; this was one way of coping or meeting with the situation.

Approaching the Situation

In addition to those who sought to explore the situation for 'hope grounds' discussed earlier, approaching the situation involved finding something positive in it, and drawing upon personal resources to cope with it - these included trying to think positively - fighting negative feelings, using humour and activity, and making preparation for death. Approaching the situation statements were made by fourteen (27%) of the hospice random sample and four (18%) of the hospital sample.

Mrs G (Hospice) provided an example of trying to find something positive in the situation. Her husband had broken down in trying to care for her, she said of her admission to the hospice:

'Helping Fred - that is one good thing I have to think about'.

Mrs O (Hospice), 'I think of other people and realise that many are worse than me'.

Refusing to give in meant exercising control of the self and not giving in to feelings. Mrs E (Hospice):
'You have got to be a fighter - if you give in my dear you have had it'.

An example from the convenience sample was given by Mr AD (Hospice):

'If you don't appreciate things at this stage of life and the condition you are in you might as well not be here at all'.

Approach was also expressed in the form of drawing upon personal resources to cope with the situation:

Mr M (Hospice), 'It's ... really up to yourself'.

Mr K (Hospice) 'You make the best of it'.

Another resource was humour, used particularly by two patients in the hospice and two in the hospital. For example Mr PE (Hospital):

'Have a good laugh - because if you haven't got a good laugh you haven't got nothing in hospital'.

Activity geared to making acceptance easier was seen by Mrs J (Hospice) as eventually enabling her to come to terms with things:

'I have to accept my situation ... doing something positive and active in therapy I will sort myself out'.

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Miss ID (Hospice) 'There is no point in being alive if you are just snoozing - there are lots of things I want to do'.

As discussed in chapter 12 others had prepared, or were preparing for death by settling up their financial and family affairs. This was not only a means of providing for others but a way of coping. Five patients in the hospice talked of the active preparations that they had made. For example, Mrs L (Hospice) said of her situation and of being kept pain free:

'Until I disintegrate into nothing - doesn't bother me - everything I want to do I have arranged.'

Avoiding the Situation

In contrast to the behaviours cited above which approached the disease situation, another means of coping was through avoiding it as much as possible through temporary diversion and 'escape'. Avoiding type statements were made by twelve (23%) of the 'hospice' random sample and one (5%) of the hospital. (These were in addition to statements made on avoiding the ward and other patients, which are discussed in chapter 11). Temporary escape could be found in the forgetfulness of sleep - Mr C (Hospice) was feeling stressed and had no visitors to act as a diversion. He said:

'All I hope is that I have a good sleep.'
It could also be found in diversionary activity, for two this was having a cup of tea, and for two having a cigarette. Both were important to Mr P (Hospice):

'Having cigarette. Tea - hot cup helps'.

Being able to engage in activity that was as 'normal' as possible was another means of diversion. Diverting the mind included talking with others about something other than current worries. The research was used for this purpose as people talked of things other than the illness that mattered to their quality of life. For example:

Miss A (Hospice) was anxious and sad. She said, 'Somebody to talk to - What about? - 'Other things - not illness’

Mr U (Hospice) was also very sad - he talked at some length about his interests, world politics, education, changes in life over the years, and indicated his pleasure in being able to do so.

It was important to their quality of life that these sick people were able to 'get away' from thoughts of their illness.
CONCLUSIONS

This large body of response on hoping and coping, spontaneously given in reply to the quality of life question, indicates the importance of these concepts to the quality of life of respondents. Hoping and coping has many facets; and avoidance as well as approach was important at the time to many. The statistics that have been given have related only to overt statements on hoping and coping. In addition many respondents demonstrated that this is what they were doing by their behaviour at interview, for example, they were sharing their feelings, talking of positive things, and could be objectively defined as engaging in hoping and coping activities. Only in three of the hospice sample could no such activity be detected - these were the people, who at the time were particularly immersed in the misery of loss.

Similar types of response have been found in the hospice and hospital. A higher proportion of hospice patients made avoidance statements, this may have been because of the greater awareness in the hospice sample of the situation, and also the effect of being surrounded by the deaths of others. At the end of chapter 8 it was indicated that some male patients appeared to exhibit more intense distress, and that this distress had been 'bottled up', in this chapter a smaller proportion of men in the hospice 'random' sample spoke of hoping and coping. Gender differences will be discussed again at the end of section V. It was also noted in chapter 8 that to be young and dying was an additional distress for some; in this chapter it is noted that old age could form the basis for lessening distress through reducing expectations.
To hope for life was important to quality of life and hoping could be reduced; chronic ill health and peaceful dying could be accepted as different hope, when the hope to get better could no longer be maintained. It was noticeable however that whilst a number of fall-back positions were taken with regard to life itself none were offered with regard to the hope for comfortable dying. The expectation of comfortable dying, when hopes for life are fading, is therefore a most basic quality of life factor, a basis for hoping and coping.
Chapter 8 has explored the emotional distress associated with advancing illness and chapter 9 the need to hope and cope. Given the importance of these hopes for life and health an issue of concern to patients of key relevance to their quality of life, was the information that they received about their condition; both in terms of what was told and the way it was told. This chapter explores this issue in which the response suggests that an important aim of care should be to be sensitive to the patient’s needs for information about the illness. It also draws on some additional research undertaken within the hospice convenience sample to ascertain the kind of doctor that patients felt they could approach to provide honest and appropriate information.

SENSITIVITY TO PATIENTS’ NEEDS FOR INFORMATION ABOUT THEIR ILLNESS

The subject of what to tell the patient has been the focus of research for more than two decades. Patients have often been found to suspect that they are dying though they were not informed (Hinton, 1972); and to wish to know more than their doctors have been willing to tell them (e.g. Gilbertson and Wagensteen, 1962; Goldie, 1982). Whether a patient is to be told of a poor prognosis or not is primarily seen as the responsibility of the doctor (Mason and McCall Smith, 1987; Field, 1989); legally a doctor owes a duty to answer questions put by a patient but has no duty to provide information when not asked (Brazier, 1987).
It is not surprising that despite the need of many dying patients to know of their prognosis, doctors are still reluctant to give bad news, although less so than in the past, for the giving of such news is traumatic for all concerned. As Goldie (1982) states:

'A patient may be given bad news in many different ways - none can make it good!' (P. 129).

Reasons given for doctors' reluctance have related to the moral obligation not to harm the patient, to the belief that the patient does not wish to know or cannot understand the truth, to the ultimate uncertainty in making an accurate prognosis, to a dislike of coping with the resulting emotional distress, as well as to the doctors own personal fear of death and fantasies about the patient's likely response (e.g. Glaser and Strauss, 1965; Cartwright, 1973; Goldie, 1982). Failure to communicate information to the patient at a time when a patient desires it also stems from rigid hospital hierarchies in which the junior staff most close to the patient may not be empowered to discuss prognosis.

It is now frequently advocated that patients should be given the information that they desire, for the giving of bad news may also have beneficial effects. From a background of specialising in psychotherapy for dying patients Goldie (1982) states:

'It is indisputable that most people suffer anguish when they learn that they have a fatal disease ... Far less obvious is that such information causes more harm than good, for against the anguish must
be set such benefits as: relief of uncertainty ... the possibility of informed reflection and discussion about the likely course of events; the opportunity to take stock, mend bridges, make farewells, arrange affairs and even help family and friends to come to terms with their loved one's impending death; the avoidance of the extensive web of deceit in which an initially limited medical (or family) decision to deceive often results - deceit which may supplant a lifetime's trust; and finally the amelioration of the process of dying which honest preparation for death may achieve'.

(P. 116).

For these reasons it is recognised in the speciality of terminal care that the patient's questions should be answered with information honestly tailored to the query, but that the patient has a right not to know as well as a right to know (Feigenberg, 1980). Allowing the patient to lead the way in questioning permits the information to keep some degree of proximity with comfort producing defence mechanisms; and offering support at the same time offers hope of comfort in a future that could otherwise appear completely bleak. The timing of 'telling', the nature of 'telling' and the manner of 'telling' are all important (Goldie, 1982). Parkes (1984) suggests that it is better for psychological well-being in a slowly progressive disease if patients are able to come to terms with a series of hope disappointments rather than receive one major hope shattering blow. Such a shock is likely to erode the mental and physical activation upon which hope is based (Miller, 1986). The response in this study confirms the importance of these principles to the patient's comfort and quality of life.
RESEARCH DATA - FINDING OUT ABOUT A POOR PROGNOSIS

A variety of different situations were encountered in the research with regard to the information people had received about their prognosis; four patients in the hospice 'random' sample (8%), and seven (32%) in the hospital sample talked spontaneously and directly on this issue, as well as others in the hospice convenience sample. From this response several types of situation emerged with regard to knowledge of the seriousness of the illness which are typified as:

1. Wanting more information.
2. Satisfied to have been informed.
3. Sorry about the manner of being informed.
4. Information denied.
5. Hedge of secrecy.

1. Wanting More Information

Five of the hospital patients were concerned that they were not being fully informed by hospital staff of their situation; they were afraid that something was being held back. For example:

Mrs PL (Hospital) 'Answer your questions honestly when they say you are going to get better?'

Mrs PA (Hospital) 'When they tell you, you are getting better - tell you true?'

Mr PA (Hospital) 'They say it is the calcium but I am sure there is something more sinister'. At the time of interview a doctor came to
check his drip - Mr PA began to question him. The quick reply was, 'Oh, you worry too much'. It was not known whether the doctor came back to talk with him further.

Mr PE (Hospital) felt information was being wrapped up in medical jargon. He said,

'The doctors should explain more in terms you can understand'.

Mrs PF (Hospital) exemplified the fraught situation in the family when information is withheld from the patient. She was conscious of a rift that was developing between herself and her family and was conscious that this was exacerbated by her reactions. This left her feeling angry and guilty. She had been talking of her pain and said:

'They say it is the cramp - things like that start upsetting you - family accounts do not tie up and you think that nobody cares - it's not true at all when you think about it - it's naughty. I don't go out of my way to be nasty or do this or that - it's very hard at times'.

These patients, representing almost a quarter of the hospital sample; all felt that it was important to their quality of life to be better informed. Since this was spontaneous comment, not probed in any way, it is likely to under-represent those who experience a deficiency in communicating with hospital staff on the vital subject of their prognosis.
2. Satisfied to Have Been Informed

Four patients in the hospice 'random' sample and two in the hospital sample, talked of being told that their condition was fatal - three of these talked of having to encourage their doctors, for they had sensed a diffidence. All expressed a satisfaction with having been told; for this had met needs to be relieved of uncertainty, to make arrangements, and to be treated as responsible. For example, Mrs F (Hospice) was ready to have confirmed what she already suspected, and she needed to know in order to make arrangements for a handicapped daughter. After she had been told of her condition she was able to make these arrangements and focus very positively upon getting the most out of the life that was left. She said:

‘In the last hospital the consultant kept telling me bits and I said, Why? He said he was trying to lead up to telling me I was not going to get better’.

Mrs L (Hospice) also needed to know in order to make arrangements, and in order to retain her sense of identity as being in control of her life. She perceived that others had misjudged her ability to cope.

‘People think I should be absolutely devastated but I am not - should be flooded in tears they think. Everyone was going round it - left it to my GP to tell me. I said..I am not going to run a tantrum’.

As discussed in chapter 15, to be informed honestly was also essential to Mr R (Hospice) for this indicated to him that he was being treated as
rational. This was particularly important as he had a brain tumour, and was afraid of being treated as less than responsible. Once he knew of his prognosis he was able to share with his family and they gave each other mutual support.

Two patients indicated that the manner of telling had been important to them. Mrs PN (Hospital) said with gratitude, 'I was told very gently and kindly'.

Miss C (Hospice) was left with some hope and the knowledge that she would be supported. She said,

'Doctor X (Hospice) said, "we can't cure you - but we can make the best of what we have got"'. She was accepting of her situation.

The inference was that these people had been told as much as they needed to know, and were ready to know at the time. All had an awareness that their illness was in its final stage but there was no suggestion of being given a time for dying. All expressed a degree of acceptance of the situation and there was indication in each interview that some satisfaction was being obtained from life. It had been important to their quality of life that they had been told in the way that they had been told.

3. Sorry About Being Informed

In stark contrast to those patients just cited, whose lives were enhanced when their request for information was sensitively met, were two in the
hospice convenience sample who had been devastated by being informed of their prognosis. It appeared to be a matter of imposing too much information upon them too early. There was no hint that this had originally been requested, nor any suggestion that the telling had been accompanied by an offer of continuing support. Miss LD (Hospice) had been given a life expectancy in terms of a specific number of months by a doctor in her past hospital. Although she still valued many aspects of the life she was living, she felt her quality of life had been ruined; it was the specificity that had devastated her rather than general information that she was unlikely to get better:

'I don't think anyone ever knows - for a doctor to say six months or a year - they should not stress too much but can say - "Yes, you have a terminal disease". At the hospital they told me a time. It is like having a death sentence'.

She had tried to get the hospice doctor to refute this prognosis:

'I asked the young doctor here and she suggested I put my affairs in order - remission - this does happen. It's like being in a cell under a death sentence and you do not know whether you will be reprieved'.

When Miss LD was asked to assess her quality of life she said:

'I don't think that we have any quality of life because that involves looking into the future and we do not have one'.
Frankl (1963) emphasised that it was a peculiarity of man that he could only live by looking into the future.

It appeared that Mr CD (Hospice) had been told too much too early and had been unready to cope. His immediate response to the quality of life question was:

'Yes, I would like to talk because what I may say will help someone else (started shaking) - you can see how I am. I was alright when I first heard that I was dying (a year previously) - got all my business organised - decorated the flat from end to end - then I suddenly cracked. It is the knowing that I am dying and the waiting - being condemned. I could take a pill - in fact did try and commit suicide and was rescued by a whisker - it's the waiting - I wouldn't do it (again) because of my wife - she has been wonderful to me'. (First response)

Mr CD was given emotional support at the hospice and started to go home for the week-ends in preparation for a full return there. He said of this help:

'It is not that they have done anything special - I think it is the kindness. I saw my father in a geriatric hospital - there just waiting to die. It is not like that here - you can see we are all up and doing.'
Mr CD was able to contend with his situation for he felt supported by family and professionals and felt secure in the knowledge that life could be lived to an end that held the likelihood of being comfortable. He ended the interview with the statement:

'When the time comes I would like it to be here; it feels safe'.

4. Information Denied

Only one patient in the hospice convenience sample mentioned having been denied the information that he needed at the time that he needed it; although this may have been the experience of others, which no longer influenced their quality of life. Mr CX (Hospice) had attended hospital out-patients and had asked the doctor about his condition. He described the doctor's response:

'The doctor touched me on the arm and said "See you again in a month"'.

Mr CX was still angry when he talked of this; a month is a very long time to wait in uncertainty, but he did not feel that it would be any better even a month later for he perceived this to be a polite fob-off. In these circumstances he was particularly incensed by the placating touch on the arm; an attempt to conceal insensitivity with a show of sensitivity. He saw this as an insult to his intelligence and said,

'I am old enough to know if someone really wants to know'.
Mr CX was not of high occupational status and gave the impression that he had received little education, yet he had learned the rules of social interaction in the experience of life and knew how to interpret them. His conclusion was that this was a doctor with whom he could not communicate.

5. Hedge of Secrecy

The two patients discussed here were different from the other groups in that neither were asking about their condition. Their medical records, however, indicated clearly that they had been denied information about it; that a hedge of secrecy had been built around them ostensibly to protect, but eventually to bring distress.

The records of Mr K (Hospice) noted that on admission to the hospice he neither knew of his diagnosis or prognosis although he had been diagnosed a year earlier. His children had united to prevent him or his wife from having information about his serious condition and he was 'the good patient' co-operating in every way that he could think of to achieve health. His first interview commenced with the statement:

'The most important (quality of life factor) my wife and myself should get better - this is the most important thing my dear for both of us to get well and live a normal life'.

At the second interview a week later when he was deteriorating there was a marked difference - no reference to getting better but only a sense of great sadness and fear. He could not bear to be left alone. He died a few days later and as far as was known (and staff discussions were attended)
died without being able to share with his family or anyone else. In his attempts to be the 'good patient' and do only what he was told to regain his health he may also have denied himself some of the pleasures of living.

The situation of Mr C (Hospice) was basically similar; his records described the protective screen that had been drawn around him by his family. He had only been diagnosed four months previously but his cancer had advanced rapidly. He was stated on admission to the hospice to have no idea of his diagnosis or prognosis. Relatives wished to protect him from knowing and he had not asked. When arrangements had been made for his transfer to the hospice he had been told he was going to another hospital; the nature of the work of the hospice had been hidden from him. Mr C's first response to the quality of life question was:

'LIFE - TO GET WELL - TO GET OUT OF HERE - TO GET HOME TO MY DEAR BELOVED - THAT IS THE ONE THING - TO SETTLE AGAIN - I DON'T KNOW IF THIS IS ASKING FAR TOO MUCH - I DON'T KNOW'.

At this first interview Mr C was voicing a query in a non-threatening situation in which the researcher was not expected to provide, or necessarily to know the answer, but he was not asking staff. A week later, as discussed in chapter 8, he was exhibiting intense fear but was never able to talk about it to others. A few days later he died without being able to share with the wife he had loved so much. Both of these patients felt isolated and were amongst the most fearful.
There may have been many factors contributing to the situation of these two families; the family members might have been unable to cope themselves with sharing bad news and might have been correct in assuming that the patient would be devastated to learn of the seriousness of the illness. However, even if this had been the case, pretence becomes less convincing with deterioration. If they had asked staff about their condition then they would have received honest information for the policy of the hospice was always to respond to the patient. At the end both, of these patients badly needed to share their distress but may not have been able to break down barriers of their own and others’ making. To some extent they used the anonymity of the research. The isolation diminished their quality of life and perhaps that of the families in their bereavement.

Creating a Climate for Good Communication

The findings in this chapter so far indicate that although the professional maxim to allow the patient to take the lead in questioning is a most useful one, it is also rather simplistic in a complicated interactional situation; for the patient may be discouraged from asking, by the family, or knowingly or unknowingly by the professional. As has been noted patients were very quick to sense diffidence on the part of their doctors - verbal and non-verbal communication all played a part. The response of a further hospice convenience sample of seven patients of whom Mr CX was one, indicated some of the factors that enhanced the patients willingness to approach the doctor. They were asked, 'What kind of doctor puts people off talking to them?' and 'What kind of doctor encourages people to talk or share with them?' (Appendix 6) Two main
themes emerged; these related to the personal qualities of the doctor and to the perception of the doctor’s readiness to respond.

The personal qualities that encouraged communication were said to be friendliness (2), gentleness (1), compassion (1), and empathy demonstrated by interest in the patient’s problems and feelings (2). Mr GX (Hospice) described a friendly approach:

‘A doctor who coming to you says - "Oh good-morning Cyril, how are you?" - friendly in his tone’.

However a doctor might be warm and friendly and interested in the patient’s problems, but this alone would not assure readiness to give honest and accurate information. This was seen to require professional competence (2), the willingness to be truthful (2), and to have time, or be willing to make time even when this was not readily available (2). Of the doctor who had been honest with her, Mrs CX (Hospice) said:

‘A doctor that will answer your questions truthfully - mine never fobbed me off about cancer’.

Mrs FX (Hospice) perceived that the doctor was willing to respond when he made time for her:

‘Had time - didn’t really have time - but appeared as if he had’.
Personal qualities that discouraged were coldness (1), unwillingness to consider the patient's point of view (1), and doctors who appeared to expect to be treated like 'gods' (1). All of these characteristics set the doctor apart, emphasising the relative powerlessness or inferiority of the patient.

Mrs EX (Hospice) said, 'Being cold puts a barrier up'.

These remarks from this very small section of this study indicate the perceptiveness of these patients and the degree to which they assessed the fitness of doctors to be approached with questions that were vitally important to them. They indicate that the right climate has to be provided if patients are to be encouraged to share problems and make enquiry about their situation.

CONCLUSIONS
The findings in this chapter and the previous chapter, with regard to communication of prognosis, indicate that for some patients their quality of life at the time meant hanging on to hope and avoiding bad news. For others it meant having an understanding of their condition and making preparations. Information had been given with beneficial and harmful results. This indicates the extreme sensitivity of this issue and the need to gain as good an understanding as possible of exactly what the patient really wants to know. This suggests that the decision as to what to 'tell' and when to 'tell' is often far from easy and should be a team one, particularly involving the staff, often the most junior, who spend most time with the patient.
These findings do not support the blanket approach of one doctor once encountered, who insisted that his firm policy was to inform all patients as specifically and as early as possible of their prognosis, whether asked for this information or not. Whilst such an approach might be conducive to encouraging acceptance of treatment, on the findings from this sample of terminally ill patients it would not be conducive to quality of life. The system of waiting for the patient to indicate that there is a query is however, dependent upon there being an environment encouraging to enquiry; patients have to feel free to question and be confident that the reply will be truthful. Attention has to be paid to all parts of the interaction.

The situation of the two patients surrounded by a 'hedge of secrecy' suggests that the family are also part of this interaction, and that, at least for some, relationships could be helped if issues of communication were explored earlier on in the illness. When patients are admitted to a hospice a few days before death it may be too late to break through the barriers that have been erected over a long period of time. Both of these patients wished to share distress and did use the research to some extent for this purpose. In this type of situation it might assist this expression if friendship were offered by selected volunteer visitors who would be 'safe' to talk to because they would not be in a position to confirm that which was too difficult to be directly confronted.

As has been seen, the issue of 'telling' has ramifications, not only for the relief of the distress of uncertainty, but for the patient's self-esteem, ability to take control and make arrangements, and ability to
find hopes based on solid grounds. The research indicates however that imparting bad news is not a simple or easy issue for anyone concerned in the interaction; and all the discussion over the years confirms this. To try to tailor 'telling' to the individual is however of real importance to quality of life.
As has been discussed in chapter 8 there was much emotional stress associated with advancing disease and this diminished quality of life. However this was only part of the stress experienced for institutional living could also be demanding and traumatic.

The Concerns of Institutional Living

The concerns of institutional living centred around routines, the problems of living alongside other patients, boredom, and safety issues. Table 11.1 notes those respondents who spoke of these actual or potential stresses.

Table 11.1 Actual or potential stresses in the institution discussed by hospice 'random' sample and hospital patients.

<table>
<thead>
<tr>
<th></th>
<th>Hospice n = 52</th>
<th>Hospital n = 22</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Routines</td>
<td>11</td>
<td>21</td>
</tr>
<tr>
<td>Other patients</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>Boredom</td>
<td>7</td>
<td>13</td>
</tr>
<tr>
<td>Security issues</td>
<td>10</td>
<td>19</td>
</tr>
<tr>
<td>None discussed</td>
<td>27</td>
<td>52</td>
</tr>
</tbody>
</table>

Percentages do not sum to 100% as some patients expressed more than one actual or potential stress.

More of these concerns were spoken of in the hospital than the hospice, except for those relating to routines. This suggests that the hospital patients were more aware of these concerns as an actual or potential source of stress, and that the hospice minimised them.
The Need for Comfort

If quality of life was to be maximised in institutional living then relief had to be found from these stressful issues; the means of relief can be seen as forms of comfort; for to comfort is to relieve or to alleviate. Comforting has many connotations - to comfort is to strengthen, relieve from distress, soothe, cheer, give enjoyment, provide freedom from annoyance or vexation (Chambers, 1973:260). Some forms of comfort relieved more than one type of stress, for example, freedom of the ward could relieve boredom, loneliness and the problems associated with living alongside other patients. The comments of these dying patients suggest that comfort should be an important aim of care if the patient's quality of life is to be maintained.

COMFORTING THE PATIENT

Patients indicated that the stresses of institutional living were relieved in several ways. Six main types of comforting emerged in the response. These were:

1. Comforting - minimising vexation and maximising freedom.
2. Comforting - creating a feeling of security.
3. Comforting - creating a friendly, happy atmosphere.
4. Comforting - Bringing interest and enjoyment into life.
5. Comforting - empathising.
6. Comforting - balancing inability with ability.
1. Comforting - Minimising Vexation and Maximising Freedom

Minimising the vexation of restrictions and maximising freedom could comfort the problems of coping with routines and the problems of living alongside other patients. These aspects of institutional living could be very stressful.

The Problem of Restrictions and Routines Adjusting to a new environment was not easy - it meant facing restrictions in living. Mrs PI (Hospital):

'When you are at home you can sit at the table when you like - can make a cup of tea - friends come in'.

It meant trying to adjust to the unfamiliar - Mr R (Hospice) had only been ill for five weeks and was still bewildered, his life had changed so rapidly:

'It is all unusual for me to be in a hospital - unusual'.

It meant trying to cope with routines that could be uncongenial - Mr K (Hospice) said:

'They get you up (wake you) very early here - 5am - so I am getting used to the surroundings'.

Mr N (Hospice) 'Done by the clock - do you like the feeling? - not particularly but lets face it in a hospital it can't be done
without', and here Mr N comforted his feeling by adjusting his expectations.

The more care that was required the more it was necessary to fit in with the needs of others needing care. After the experience of freedom from such necessity Mrs F (Hospice) was, in her final interviews, looking toward 'the time when I shall be in bed' and she joked about it:

'Having your pillows plumped up at 5am to be ready for breakfast at 7am'.

The responses from two patients indicated that they found the routine of the hospice more onerous than that of the hospital. For example, Mrs N:

'The meal times are wrong ... Ten to five to serve supper - last meal - why can't we be like other hospitals?'.

The Problems of Living Alongside Other Patients A considerable amount of distress came from having to live alongside other patients in a restricted space. Mrs GD from the hospice convenience sample expressed this:

'Put in a ward with people of different cleanliness and colour'.

Nearly a quarter of the patients in the hospital and over a tenth in the hospice 'random' sample, with others in the convenience sample made some comment on the negative impact of living in a restricted space, or being
in the presence of other patients. Both the small bays of the hospice and
the large wards of the hospital could be oppressive. Mrs N (Hospice) who
had been transferred from a larger hospital ward found the bay hard to
cope with for it was too restricted, this was a continuing theme:

'A nasty shock - I feel not exactly pushed out. The nurses do their
best to keep you bright but they cannot be with you all the time -
when I was in X there were twenty beds - always something going on -
you want more life'. (First response - first interview).

'Sometimes for an hour we three are on our own - makes me go barmy'.
(Second interview).

The presence of other patients could be disturbing when it involved lack
of privacy - Mrs GD (Hospice):

'When the doctor does his rounds - everyone listens to all that goes
on'.

They could also be annoying; in both samples complaints about other
patients were made entirely by men, 4 (18%) of the men in the hospice
'random' sample and 3 (43%) of the men in the hospital. The noise of
personal equipment, and other activity was annoying. Mr PG (Hospital):

'I tell you what I object to - these individual small TV sets that
people take in themselves. They leave it on and doze off to sleep -
when they put it on they never think of pulling the curtains - they
would be alright if people would just use them properly - it is no use turning them on and going to sleep - don’t need to have sound up - have things for ears’.

Mr M (Hospice) 'Sometimes it is noisy - the music has been on non-stop all morning - someone has a tape on - it gets a bit much’.

Mr PD (Hospital) 'The complaints are the other patients - someone talks very loudly. However, Mr PD was at least glad not to be among the young and said, 'Lucky to have older men in the ward - I love children but some of the younger!'. Mr PD was very glad that the bed rest that he needed gave him some respite from the day room, 'Was delighted when they said I needed bed rest - did not have to go along to the day room and sit with the other patients'. He did not indicate whether the pressure to go to the day room emanated from staff or from other patients - a probe here would have been helpful.

Day rooms, provided to give some relief from the ward, can instead become traps where, with the small space between seating, patients can become even more vulnerable to each other.

Whether windows should be open or shut could be a bone of contention, this was mentioned by two men. Mr H (Hospice) was annoyed with a patient who had demanded that the doors and windows be opened. He said, 'He did not ask us'.
Living alongside others involved having to listen to depressing opinions and experiences:

Mr PA (Hospital) 'Not to listen to the rubbish of other patients'

All these things could be particularly stressful to those who had lived on their own. For example, Mr I (Hospice)

'I like to be in an alcove on my own - I have lived on my own - was discussing whether to move to a bed near the window'.

Another form of distress in living alongside others was that of watching their experiences. Mr PD (Hospital):

'The poor boys in this ward have all had dreadful operations. Yesterday looked quite normal - then given jab - wheeled off by the sinister looking men - come back with a bag of saline - specks off - teeth out - looked dreadful ... it's the other patients that are the problem in hospital'.

Reference to the impact of the dying of others came from four women in the hospice 'random' sample and two others in the convenience sample there. None came from the hospital, where it appeared to be a practice, at least in some wards, to put the dying in a side-room. For example, Mrs N (Hospice) said:
'All I have to do is to sit here and watch people die, it does not cheer me up at all'.

In an institution such as St Joseph's there can be almost a waiting room effect in waiting to die. Mrs T (Hospice) said,

'The lady in that bed died last night - I didn't hear anything - thought that’s one of us gone out of here'.

This effect is likely to be less in those hospices that are able to admit more patients for short periods and then discharge them home. However, the hospice is there to serve the local community and its policy is to a great extent determined by local demand. The demand around St Joseph's was not only for specialist symptom control but for beds for people to die in.

**Freedom as a means of comfort** The form of comforting found to be most appropriate to feeling restricted by routines was to have as much choice and control as possible within the framework of care. Control has been discussed in, chapter 9 as a means of coping; it is a recurring theme. Mrs L (Hospice) expressed this generally:

'If everybody lets me do what I want that is fine by me - I don’t want any restrictions'.

The freedom often appreciated in daily living was associated with food and drink. Although meals might arrive at regular and rather odd times it
was important to be able to have a cup of tea when desired and snacks made, or special food brought in, and to refuse the institutional food when desired. For example, Mrs A (Hospice) said:

'The freedoms that we have here - if I wanted for breakfast - I am a bit of a fusspot - like cold instead of hot milk - whatever is your fancy you can have it - like eggs boiled 2½ - 3 minutes - at the other (hospital) we could have a game of football with them. Any of the ladies who want anything special can have it - you could have a drink - alcohol brought in'.

For two others it meant not being bound by rules relating to when to get up and stay up, and when to go to bed. As noted in chapter 7 freedom for Mrs A (Hospice) meant freedom to go to bed when she felt tired, for Mrs PD (Hospital) it was freedom to stay up:

'Stayed up to watch the television - nobody said I should be in bed'.

For some who were ambulant, freedom meant being able to roam as far as possible - in the buildings - garden and further afield - to go home for short spells. In the hospital the references were only to freedom within the ward, although patients were seen to visit the shop and other public areas there. This freedom could bring more interest into life, help in the finding of patients that were congenial as well as help in the avoidance of those that were not; and provide some space to talk more
privately with visitors. It was also a means of escape from watching the
dying of others:

Mr K (Hospice) 'Out for three hours'.

Mr PE (Hospital) 'When you are in hospital it is the freedom of the
ward that matters'.

Mrs PN (Hospital) 'If you don’t want to have anything to do with
others you needn’t - no restrictions'.

For Mrs N (Hospice) the freedom to roam the hospice meant all of these
things, and it was a recurring theme:

'To see different people - visit the tea bar - get away from the
curtains - you must see different faces around - different
movement'. (Second interview)

'Need to see different faces around - yesterday I went upstairs (to
a service) - they did it up so lovely ... have asked for more ... I
miss Carol (another patient) ... went to St Patrick’s (another ward)
- there were about twenty of us there ... I could see all the
traffic going past - makes a world of difference'. (Third interview)

'Companionship - still going (to other wards) every day (although
deteriorating)'. (Fourth interview)
To be able to escape from the traumas of the ward - from other patients, was very important for this was often the only form of escape possible. As Mrs I (Hospice) stated, she could never escape from her illness. Consequently she was upset when the escape to the ward balcony was temporarily impossible because the sun blind would not work. Part of the comforting to be found in the institution was having the freedom and ability to escape some of the things that were irksome and distressing.

2. Comforting - Creating a Feeling of Security

Creating a sense of security meant addressing the fears of dying as well as creating an environment in which the patient felt safe. Addressing fear meant listening for the questions patients might be trying to ask and being open to discuss issues around which fear centred. As noted in chapter 9 patients who knew they were dying were asking questions about their own symptoms and that of others - to be able to explore fear was one means of being comforted. Mrs Q (Hospice):

'We need more talk about how people overcome their fears'.

The deaths of others, peaceful though they were, could raise disturbing feelings. Mrs D (Hospice) was disturbed by the activities of staff after a death, as well as by their silence towards it:

'That night it seemed a hole in the corner business. No nurses talked about her the following day, although one had been close to her, and came back in her off-duty to be with her. She just
disappeared - all I heard was a crashing and bumping of trolley wheels'.

Miss LD (Hospice) also raised a point about frightening secrecy:

'They should be a little bit more open about death and what it is - in being secretive it makes it frightening. They could explain when someone dies that the death was painless - or - be truthful. I would like them to come and say "Mrs So and So has just died peacefully - or - was in a bit of pain - you imagine all sorts of things. But then all people are different - they could make a judgement of their own about the patient'.

Comforting meant a careful listening and responding to what the patient really wanted to know, bearing in mind as noted in chapter 9 that there could be ambivalence in this wanting. It meant explaining procedures and treatments. For example Mr B (Hospice) said:

'They explain everything that they are going to do from beginning to end'.

Mrs PN (Hospital) 'You come in confused - not knowing - yet they explain and are so gentle ... the main thing is that if I came in again I wouldn't be frightened'.
Comforting meant addressing fear as it was presented, as well as listening for what might lie behind. For Mrs N (Hospice), fear took the form of claustrophobia, and her nursing care was fitted around her need to get away from the curtains that surrounded her and other patients receiving care. For her these were symbols of frightening isolation.

'I am frightened in the night - every day I ask to be washed first because I can't bear the curtains around me for long - it makes me feel claustrophobic'.

Mrs D (Hospice) had come to trust certain staff and their presence in the ward comforted her fear of being separated from people. The action of two nurses formed the basis of her second quality of life assessment:

FEELINGS ABOUT QUALITY OF LIFE AT PRESENT.

<table>
<thead>
<tr>
<th>Delighted</th>
<th>Terrible</th>
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'If you had asked me yesternight it would have been different (higher) - the two ladies who are on night duty are very good and work together - I have no fear when they are there - when they are not with me they talk to me through the partition. The mark would have been on "delighted" - there when I needed them - I did not expect that they would be so kind and charming and quiet. I hope that they will be here to-night'.

Addressing fear also meant creating an environment in which people could feel safe; four indicators of a safe environment appeared in the comments.
of these patients - (a) ready availability of staff, (b) cleanliness of the environment, (c) quality food, and (d) adequate fire precautions.

a. Availability of Staff Reference to the availability of staff was made by seven (13%) of the hospice 'random' sample and six (27%) of the hospital sample. Miss ND (Hospice) described what it had been like to be left feeling helpless and afraid in the hospital that she had just come from. She was partially paralysed and subject to fits, and felt on the first occasion that the nurses had thought she could manage because she was so much younger than the other patients in the ward:

'The worst experience - the nurse saw a young face - even if it had arrived in a wheel-chair - I walked into the day room - overbalanced - fell - yelled for ages. Eventually I forced myself up. It (the day room) had a fire door (cutting out sound). On another occasion the nurse helped me into the bath and forgot about me. The bath water was getting colder and colder - door shut - a warning buzzer carefully tied up on the ceiling. I shouted and shouted and it left me with a dreadful fear of baths'.

Some symptoms could be particularly frightening. Miss B (Hospice) had gladly traded off her home for the hospice because of fear:

'Used to live alone - and choke in the night'.

It was important to quality of life to feel that a doctor was readily available. Mrs PK (Hospital):
'If you want a doctor they come right away - they are very good - you don't feel as if you are alone - loneliness ... is a frightening thing'.

The night was a time of maximum vulnerability when staff availability was particularly important. These statements underlined the importance of night staff. Mrs A (Hospice):

'So well looked after in the middle of the night - you feel security'.

Mrs PE (Hospital) 'At night you need only press the buzzer - they will come when they can - they are walking up and down all the time - you always know that there is someone around'.

However, as some statements indicated it was not just the availability of anyone that mattered for fear to be assuaged; it had to be availability of trusted people. For Mrs X (Hospice) it was knowing that there were trained staff around:

'The nurses are qualified'.

For Mrs PE (Hospital): it was having those she had learnt to trust:

'You wake up and you see familiar faces - have confidence in certain ones - feel you (can) trust - you must have someone to trust'
It was therefore possible to feel extra vulnerable when trusted people were not around, when they had been moved to another ward or were away on holiday:

Mrs N (Hospice) 'You don't know where you are when you have a change of doctors and one of the doctors has gone on holiday'.

Such statements indicate the likely insecurity of those newly admitted who have not as yet found anyone to trust.

b. A Clean Environment To feel safe in the ward environment depended not only upon staff availability but upon other organisational factors; cleanliness was also a symbol of a safe environment noted by four hospice patients, and two from the hospital, approximately 9% in each sample. For example, Mr E (Hospice) said,

'It all depends upon the state of the hospital. I have been in two, but the cleanest care is here ... they do look after the patients'.

Mrs M (Hospice) 'Cleanliness is very important - that is here'

Frequent changes of linen were a sign of cleanliness - appreciated by two hospital patients from different wards:

Mr PD (Hospital) 'Beautifully clean - changed sheets everyday'.

Mrs PE (Hospital) 'You get clean linen nearly every day'.
c. **Good Quality Food** Another indicator of safety was good quality food that was handled well and was able of good nutritional value. Food safety rather than food acceptability references were made by two patients in the hospice and two in the hospital. Mr U (Hospice) compared the care of food at the hospice favourably with that of his previous hospital:

'Too many hands in the food...badly cooked ... burned - food here is well looked after - clean'.

Mr E (Hospice) 'Food is very important - the cooking - seeing that the person is eating decent quality food'.

Mrs PK (Hospital) 'The food here is important - milk shakes with all the calories because I am under-weight'.

Mrs A (Hospice) 'Freshly cooked food with all the vitamins'.

d. **Adequate Fire Precautions** Lastly, comforting through creating a safe environment meant providing arrangements for emergencies so that the patient could feel safe from occurrences such as fire. This was expressed in a negative way by one patient in the hospital. Mr PC (Hospital) did not feel safe:

'The fire alarm went twice this evening - I have read all the directions - the first time I went out there - don't they (management) tell them when it is OK. Another night it goes - if they have a fire here there is no-one going to know what to do. I
was there in the control place before the nurses. They don’t seem to know what happens - when it comes to a fire they won’t know what to do - people won’t know how to get out ... I am fire conscious - believe in preventing fire’.

The various statements that have been noted in this section indicate the vulnerability of patients when they feel helpless, and some of the ways in which they assess whether or not fear has foundation. Relief from such fear was a comforting quality of life factor.

3. Comforting - Creating a Friendly Happy Environment

Although it could hardly be expected that the great sadness expressed by so many of the respondents could be quickly or easily comforted by a few strategies on the part of staff, a friendly happy atmosphere brought cheerfulness into the ward and provided a basis for making friends and dispelling loneliness and boredom. Thirteen (25%) of hospice patients and 7 (32%) from the hospital spoke of the contribution of friendly, cheerful, smiling people to their quality of life - the terms most frequently used were friendly and happy. For example Mrs PA (Hospital) said:

‘Happy people, to be surrounded by - most of them are happy here’.

Mrs A (Hospice) said, ‘The nurses are so sweet and happy, if they want to burst into song they do’.
A friendly atmosphere was particularly important in helping new patients to settle well. Several patients indicated that it was important to them to make good relationships with nurses. For example, Mrs X (Hospice):

'If you can get on with the nurses that is everything'.

Mr K (Hospice) ‘I need to get acclimatised - get used to nurses’

As many patients indicated this was developing mutuality in the interaction, it was not a case of the patient being a passive receiver of care. As Mrs PN (Hospital) stated: 'It is a relationship'.

The interaction was one that was most effective when there was some mutual warmth (chapter 13 explores this further). Mrs F (Hospice):

'The greatest need is love, although medicines do quite a lot it's attitude isn't it - it's love with which you receive these things'.

(First response - first interview).

Mr E (Hospice) ‘Care and loving - care - seeing that one is well looked after - loving a job to explain - a nurse can go round and round and care but the patients could not care less’.

These statements indicate some of the emotional demands made upon patients on admission and the impact of repeated demands for adjustment made when there is transfer from one institution to another for the purpose of 'unblocking' beds in the acute ward. This was the situation of
Mr R (Hospice), he was one of approximately half of the hospice sample who had been transferred directly from another institution for terminal care. He appreciated many aspects of the change but missed the nurses with whom he had been able to build a warm relationship - now he had to start all over again:

'Finding it difficult to relate at present - to get through to the ice of the nurses here - the nurses at X used to talk with me and said they would visit me - I don't need them to visit me - but - it would be nice'.

Relationships with staff are discussed again in chapters 13 and 15, the response suggests that good relationships were a major quality of life factor.

However, it was recognised that a happy ward atmosphere did not always come easily - it depended upon staff relationships, and the ability to hide irritation. Mrs O (Hospital) said,

'If a nurse gets told off and it happens to be in front of a patient - nine - tenths (of nurses) will ignore it - if she has a tantrum and the patient hears - the patient feels not very comfortable'

Happiness was symbolised for Miss C (Hospice) by the bright appearance of the ward and its furnishings, she said:
'The moment I entered I felt this was a happy place - ward bright and cheerful'.

The happiness of staff had a vicarious quality for Mrs PB (Hospital), for despite her own sadness she could experience some happiness in their happiness.

'I have got to put up with my legs ... (the use) ... won't come back - am very grateful for happy bright staff'.

The spontaneous happiness of young nursing auxiliaries contributed much, as did the informal friendliness and spontaneity of professionals who were prepared to share something of themselves with patients. Mrs A particularly enjoyed one occasion in the hospice leisure centre:

'One afternoon it was lovely - they had some Irish dancing and songs. Father (the chaplain) he played - it was the music and the fact that we just let our hair down, so the priest let his hair down and we all joined in - you would enjoy it because it is so spontaneous - and half-way through a cup of tea. I am quite happy here ... you can speak to everyone so freely - I told the doctor how smart he looked and he said "good".

Mrs PL (Hospital) was comforted by the friendliness of the doctor. She said:

'The doctor calls me by my first name - brought me some Smarties'.
As six hospice patients indicated, friendliness was first recognised in the welcome that was given on arrival. Mrs V (Hospice) said for example,

'It was wonderful, they greeted me at the door - said we don't stand on ceremony here'.

Mrs T (Hospice) has been noted as losing the will to live before she was admitted and as waiting to die. She spoke of the welcome she had received as a quality of life boosting factor:

'It was lovely being greeted by the sister and the nurses when I arrived - they don't do that in hospital'.

Friendliness was symbolised in the willingness of staff to talk and share with patients, over and above the basic communication necessary for care, expressed as important by nine (17%) of the hospice patients and seven of the hospital (32%). For example,

Mrs F (Hospice) 'The doctors and nurses come up and talk to you'

As will be discussed in chapter 13 friendliness could develop into real friendship, and the deep sense of belonging so necessary to the quality of life of those who had relinquished their homes.

4. Comforting - Bringing Interest and Enjoyment into Life
Helping to bring some interest and enjoyment into the lives of patients
comforted boredom, and also loneliness when the interest could be shared. Ward life could be very boring, more boredom was expressed in the hospital. Five hospice 'random' sample patients (10%) and five from the hospital (23%) talked of their boredom. All but one of these ten statements were made by women. They indicated just how dreary ward life could be. For example,

Mrs PD (Hospital) 'It goes so slowly the time'.

Mrs PE (Hospital) 'The day seems long - and - the night'.

In seven of these ten statements boredom was linked with loneliness, for example, Mrs W (Hospice) said:

'Get bored - if (only) I could get up ... not very interesting (the other patients) - all a bit deaf - I am lonely'.

Handicaps such as immobility and poor eyesight contributed to boredom for they hampered communication with others as well as the ability to engage in interests. Mrs P (Hospice):

'This lying flat and doing nothing - quality of life - (means) - that I should be able to move myself about which I can't do - you wake up in the morning and you think how are you going to get through another day'. (First response).
Since two patients linked their boredom with the inability to concentrate, and both were very fearful, comforting fear may be one means of comforting boredom. For example talking about her fear Mrs Q (Hospice) said:

'I love reading but I can't concentrate'.

Boredom was relieved in the routines of care, especially when nurses talked. For example boredom was eased a little for Mrs P (Hospice) when she had a blanket bath:

'I had a lovely blanket bath this morning - all these things help to establish the day'.

When nurses were too busy to talk and there was nothing else to do then the day was dreary. Mrs PH (Hospital) had complained of the nurses being too busy:

'Nothing - there is nothing to do here'.

However, although Mrs PB (Hospital) linked the companionship of nurses with the relief of boredom she did not feel that this could be expected in a busy ward.

'Take the staff they are very very busy - you can't expect them to entertain you - now and again come and say how are you for two secs'.
In the hospital there was one reference to Bingo being arranged - this was the only activity mentioned and it was appreciated. Three references were made to the provision of television but this was not seen as contributing greatly to the relief of boredom. Mrs A (Hospital):

'Every patient gets bored - not much you can do - nurse arranged Bingo the other day on the ward - enjoyed it - TV'.

The acute ward of the hospital is a difficult place to organise interests for these may not meet the needs of the majority of its patients, who may be in for a short stay and will be recovering from surgery or other treatments. However the comments on boredom in the hospital coupled with the paucity of reference to its relief indicate that for some patients there is a gap to be filled.

The references to interests that enhanced quality of life came almost entirely from the hospice and were related to the activities of the library and leisure centre - to outings, arts and crafts, poetry, and to the music concerts. The hospice was in a very different position to the hospital for the whole of its care was geared to the chronically sick or dying, therefore it was better able to concentrate on interest needs. It is interesting to note that the references to boredom there all came before its leisure centre was fully established, once this had come about (approximately a third of the way through this project) references to the importance of its activities started to appear, these came from six (12%) of the hospice 'random' sample and others in the convenience sample. For example, Mr I (Hospice) said,
'Sister came and asked me if I would like to go to the races at Lingfield - there is always something here to look forward to.'

Mr C (Hospice) had enjoyed a short concert in the ward finding the music very beautiful; he had 'been away in a dream in the music'. This provided him with interest and escape.

The emphasis which respondents gave to their boredom indicated that it could be really stressful and quality of life diminishing; boredom could be reduced by facilitating contacts between patients as well as by helping to provide some activity in which they could be interested.

5. Comforting - Empathising

Empathy has been defined as 'the power of entering into another's personality, and imaginatively experiencing his experiences' (Chambers, 1973:423). As such empathy was another form of comforting important to the quality of life of patients. To respondents, staff demonstrated that they were entering into their feelings of sadness, fear and vulnerability when they showed kindness, concern, gentleness of manner, and when they listened and provided a comforting presence (Benner, 1984) in which they were prepared to share and receive. These were very much qualities of interaction spontaneously expressed as being important to the quality of life of by eleven (21%) of the hospice 'random sample' and six (27%) of hospital patients. Empathy and cheerfulness helped Miss C (Hospice) to accept losing her home life:
'I feel I am never going home again - but everyone is so concerned and smiling - I am quite contented'.

Mrs H (Hospice) 'I am glad I came - such kindness and sympathy'.

Empathy was symbolised by kindness; a term that was often used, for example for Mr C (Hospice) who was fearful and miserable kindness was one redress in his situation:

'They are so kind - that's what matters'.

Mrs PN (Hospital) 'Kindness and gentleness'.

Kindness was seen as a giving of the self to the patient, giving a little extra Miss D (Hospice) said,

'The kindness I receive - it is the little things that count - these people give of their time'.

Empathy was symbolised, by 'presencing', however, the time given did not have to be very great to be effective, it was quality as much as quantity of interaction that mattered. Mrs PG (Hospital):

'She (the nurse) will come up to me and put her hand in mine. She is only young - all (the) little (things) that count - they count'.

Mrs PN (Hospital) 'They cuddle a lady who sits and cries'.

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Mrs A (Hospice) spoke of the times when she needed a shoulder to cry on and the importance of having one offered, 'Sister might come'.

The kind of comfort derived from kindness, gentleness and the willingness to share distress not only soothed the hurts of the illness situation but strengthened the ability to cope.

6. Comforting - Balancing Inability with Ability

The importance of nursing care to physical comfort has been discussed in chapter 7, and will be discussed again in chapter 15 in relation to its potential for maintaining or lowering self-esteem. It was very important to patients to retain as much independence as possible and not to feel 'a burden'. However, nursing assistance also had a very comforting importance in supplying the abilities that the patient lacked, for it was distressing and worrying to be helpless. This comforting aspect of the 'assisting' component of nursing featured in the comments of 18 (35%) hospice patients and 3 (14%) hospital patients, although it was implied in many others. For example,

Mrs PE (Hospital) 'If you can't manage they will help you'.

Mrs PC (Hospital) said all they had to do was 'Ask if anything you want'.

Mr D (Hospice) 'Everybody is around me - if there is any help to be got I only have to ask'.
For Mrs JD (Hospice) the help of nurses brought some positive weighting into her quality of life:

'The nurses are so caring and attentive - that makes life worth living - gives you the will to carry on - as long as you have that.'

As it did for Mrs I (Hospice):

FEELINGS ABOUT QUALITY OF LIFE AT PRESENT

Delighted + Terrible -

The care is terrific
The nurses are caring
Illness - that's something
I can’t escape from - ever

CONCLUSIONS

In the situation that these respondents were in, so many different kinds of comfort were required if quality of life was to be enhanced. Mrs A (Hospice) summarised this in the balancing activity of her quality of life assessment. At least four types of comfort featured as positive weighting factors. In the light of these she had been able to accept dying.
FEELINGS ABOUT QUALITY OF LIFE AT PRESENT.

Delighted / Terrible

Freedom. Care. Tablets at right moment. So well looked after in night, lovely hot tea first thing. Everything fresh. Daintiness.

She concluded:

'There are no priorities - they all gather together - but I suppose having lived alone and wondering what would happen, especially in the night - it's having people around'.

These comforting factors do not usually appear on quality of life measures, although they may be implied in some broader categories associated with the patient's emotional status. As contributors to quality of life they cannot be over-estimated.

CONCLUSIONS TO SECTION V

This section is the longest of all the sections, which is not surprising since advancing disease brings a sense of loss and emotional distress to all aspects of living. As discussed in chapter 8 a large proportion of patients spoke of painful emotional responses to the disease in terms of fear, sadness, anger, shock, tension and
despair. In chapter 11 further painful responses arose in relation to the stresses of institutional living, coping with the loss of freedom in routines, the restrictions of space and the impact of other patients, as well as boredom, loneliness and feelings of insecurity.

The broad quality of life factors that have emerged in relation to this situation have been the abilities to hope and to cope, hoping and coping are inextricably linked. Much of the hoping and coping stemmed from the personal resources of patients; in this they have presented a picture of activity rather than passivity. This also applies to receiving the comfort discussed in this chapter, for to be received it has to be recognised and welcomed.

One means of facilitating hoping and coping has been the sensitive response to the patient's needs to be told of the prognosis. Appropriate telling in terms of timing and amount to be told is therefore one subsidiary quality of life factor. Other subsidiary factors centre around the comfort that was offered.

Needs Theory and the Context of Expectations and Reference Groups

The overwhelming distress of some respondents discussed in chapter 8 inhibited the awareness of other needs at a time when they were physically comfortable. Their experience is a small affirmation of the importance of emotional comfort as a second basic need in the hierarchy of needs (Maslow, 1970).
The patient's expectations have played a part in the distress of dying, relative youthfulness has been accompanied by greater anger and sadness associated with feeling deprived of life too early; conversely old age and length of illness has been associated with reduced expectations which have eased distress and helped acceptance. Role expectations have in one instance been associated with coping styles in that intense release of emotion was deemed to be unacceptable to the role and status of the respondent. Control has been important as a means of coping; control statements came largely from those with expectations of chronic or failing health. Finally the context of expectations and reference groups has elicited reference to past hospital experience. This indicated perceptions of deficiencies in sensitivity to helplessness and in cleanliness, but also in two instances reference was made to the warm relationships that could be made with nurses in busy acute wards.

Organisational Differences

Some differences were noted between the two research venues. A greater proportion of hospital patients expressed hope of getting better than in the hospice. This was not surprising since they were in a curative setting; approximately half of the hospice patients had been transferred from such settings for terminal care, inasmuch as the reason for this was understood as a need for palliative care the emphasis on terminality was heightened. Comments indicated moreover that information as to prognosis was not always as easily or fully obtainable in the hospital as the hospice.
The impact of the dying of others could be considerable in the hospice, and could be distressing, as well as reassuring in its peacefulness. This will be further discussed in chapter 13 in relation to making friends. This situation did not feature in the comments from the hospital, where it would appear that efforts were often made to transfer incurable patients elsewhere in order to free beds, or place those in the last stages of life in side-wards.

Another difference noted between the venues was the comment related to boredom. There was more boredom in the hospital and little except television to relieve it; the hospice had a range of interests through the provision of their leisure centre.

**Gender Differences**

There were some gender differences in the approach to emotional comfort. In chapter 8 it was noted that a greater proportion of women than men spoke of emotional distress and in chapter 9 of ways of emotional coping. It was noted too in chapter 8 that men expressed fear in a more intense and 'bottled-up' way. Women also spoke of the relief of crying although both men and women exhibited tears at interview. These findings suggest that it is easier for women to release their feelings in talk and through venting emotion. Other statements suggest that women tend to find comfort in involvement with other patients more than men. The references to quality of life being diminished by lack of contact came from women, all the references to the negative impact of other patients came from men. This difference did not occur however in relationships with nurses.
Inferences for Care - Organisation, Expertise, Interaction?

Organisation, expertise and interaction all have a part to play in enhancing patients' quality of life in a distressing situation.

Organisation Much of the response had an implication for levels of staffing, these are important to the time available to listen and to provide a comforting presence, although as noted it was quality as much as quantity of contact that mattered. However staff continuously rushed to almost breakdown level are unlikely to be able to give of this quality. Adequate levels of trained staff also provided a sense of security as did continuity of contact between patient and staff they had come to trust. Patients' sense of security depended also upon their perceptions as to how any possible emergency would be managed, and on whether they saw that the environment was clean, and food of good quality. Continuity of staff assisted the development of warm relationships upon which comforting depended.

Facilities for interests and relief of boredom were important, the beneficial effects of the hospice leisure centre surfaced in the research soon after its programme was inaugurated. Choice and freedom were quality of life factors that need to be built into the system. Management should also responsible for the provision of adequate expertise and for the emotional support of staff working in a stressful area.

Expertise The emotional distresses suffered by these patients indicate the need for skilled psycho-social care by those who can
counsel and listen creatively, assess the patient's needs and respond effectively to them; the family being included in the unit of care. Expertise in symptom control relieves the fear of pain and other symptoms - a team of experts are needed to provide comprehensive care.

Interaction The quality of interaction with staff, of all disciplines and all grades, was of great importance to the quality of life of these patients. The form of interaction had very little to do with expertise, or staff as 'paragons of virtue' it related rather to the warmth of shared humanity. Patients responded to spontaneity, naturalness, cheerfulness, and a willingness of staff to give of the self and chat whilst providing care. The response indicates that the importance of this quality of interaction to the patient's quality of life should not be under-estimated.

It is the combination of all these factors that relieved emotional stress and so, in a very traumatic situation, enhanced the quality of life of patients. However this list could appear to read as some form of recipe for quality of life to which patients should automatically respond; this would be too facile. As was noted, great sadness was experienced by many patients, not to experience this sadness and anger at loss would be not to have appreciated life - patients had a need to mourn and to work through painful emotions; it was a combination of the comforting factors that sustained and supported them throughout this time.
SECTION VI

QUALITY OF LIFE AND HAVING WARM SUPPORTIVE RELATIONSHIPS

OF LOVE AND BELONGING
This section focuses on warm, supportive relationships of love and belonging; spontaneously, and often intensely stated to be important to the quality of life of 38 (73%) of the hospice 'random' sample and 16 (73%) of the hospital sample. These relationships centred for respondents on the concepts of 'friend' and 'family', both inside and outside of the institution.

Friendship is defined as 'intimate acquaintance', 'mutual esteem', 'being well disposed to' (Chambers, 1973:520). Friendship therefore implies a certain depth of relationship which has a positive feeling component which is mutual. This is different from the emotional warmth, or friendliness discussed in 'empathy in care' (Section I) in which mutuality does not necessarily feature; the doctor may show friendliness to the patient as part of care, but this does not mean a friendship will develop between them. 'Family' is defined in terms of belonging to a household or group or having a common progenitor (Chambers, 1973:472); it is used, at different times, in all these senses in the data. This definition of 'family' does not necessarily have any connotation of feeling. However, for respondents, 'family' held expectations of love, sharing, and support; they identified with the understanding of the family as being the source of love, nurture and care.

Mutual love and affection, sharing and support, were therefore the key concepts that were associated with friendship and family. The
expectations of respondents underlined the definition of love as having behavioural as well as feeling components (Chambers, 1973: 778). Vanstone (1977) took a phenomenological approach to explore the expectations of love stating:

'The power to test and recognise authenticity of love is, in most people, a practical instinct or skill rather than an intellectual capacity ... That love which man seeks can be described, at least by approximation, by detecting a pattern in that which he rejects, or which fails to satisfy him'. (P. 41)

Vanstone identifies three marks or signs that deny the authenticity of love: a limitation of effort, for love implies a totality of giving; the seeking to control or possess, for love centres on the welfare of the other; an emotional detachment in which the one who professes to love remains unaffected by the relationship, for love implies a certain vulnerability in giving the object of love a certain power over the self. The first and third marks or symbols of love feature in the perceptions of respondents in their identification of warm, supportive relationships.

In this chapter the data is used to discuss issues of the relationship of the support of family and friend to quality of life. In the next chapter these concepts are related to the institution and to the orbit of care.
BACKGROUND - DYING AND LOSSES IN SOCIAL RELATIONSHIPS

Warm human relationships have long been recognised as of basic interest and importance as evidenced by the literature of love and friendship over the centuries. Love and belonging have prominence in the Maslow Hierarchy (1970) in that they are the first of the social needs. When people become terminally ill it is likely that the awareness of this need will be greater as the existential loneliness of dying is faced. As Twycross (1975b) states:

'Death is probably the loneliest experience any of us will ever have to face'. (P. 6)

The need of the dying patient for love and friendship, for warm sharing relationships, has been well documented by those who have researched and worked in this area (Keleman, 1974; Zach, 1978; Saunders 1965). White (1977) stated:

'What a human needs as he faces death is no different from what he needs in life, and love best expresses what he needs to receive and give'.

(P. 105)

It is important to note that giving matters as much as receiving.

Feigenberg (1980) noted the importance of friendship to patients, and instituted 'friendship contracts' with them. These were based on the
sharing, that in one form or another, is inherent in all friendship and described as:

'To share another person's condition of being a dying individual - a condition that is unique for each one of us yet inevitable' (P. 211).

In view of the understanding of the importance of relationships it is paradoxical that so often the patient's experience is one of increasing social isolation. Research indicates that people can die socially before they die biologically (Glaser and Strauss, 1965; Krant 1974). (This research is discussed in more detail in Section I). Krant concluded that even loved people may be dead in a social and needed sense before they are biologically so.

One approach to the exploration of social isolation is to identify the problems that bring barriers to communication. Satisfactory communication requires a willingness to communicate, adequate verbal and non-verbal language, a basis upon which to share, and an appropriate emotional climate. There is evidence to show that there are problems in all these areas for people who are dying, especially when they suffer from cancer.

Fear and Stigma

There is much agreement that the general fear of death puts a very large barrier between 'others' and the patient; for having cancer is often viewed as confronting death (Young and Longman, 1983); a reminder to others of their own mortality. Death is fearful and painful to
contemplate and there is a defensive need for denial (Becker, 1973). People with cancer, particularly those in whom it is known to be advancing, possess an undesirable social trait. Goffman (1963) describes the social effects of such a trait on interaction:

'An individual who might have been received easily into ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us. He possesses a stigma, an undesired differentness from what we had anticipated ... we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination'. (P. 5-6)

This situation was reflected in the experience of Ryan (1979), when some of his friends withdrew on learning of his cancer. Some never made contact again:

'They averted their eyes. There was silence and then they embarrassedly expressed regrets. I had become, apparently all in one instant, what from the first I had feared I might become in the eyes of some people when the word 'cancer' was mentioned - a pariah, set aside from the mainstream of life ... one can know a couple for years and suddenly find them strangers' (P. 119-120).

This situation is not uncommon for it is found in clinical practice that some patients have experienced social isolation from very early on in their illness (West, 1976).
Inadequate Language

It is likely that part of the embarrassment in such encounters is due to people's inability to know what to say. In the face of trauma, just to say "I am sorry" can be thought to sound trite; yet what can be said to bring some comfort? One approach to such situation is to search for a meaning which may be used as a form of comfort. Goffman states (1963):

> 'When the individual in our Western society recognises a particular event, he tends whatever else he does to imply in this response one or more frameworks of a schematic of interpretation'. (P. 21).

This would imply that meanings are very important and form a basis for communication and comfort. However, this age is one of many meanings and none, the continuum may range from firm religious affirmation:

> 'Yea though I walk through the valley of the shadow of death I will fear no evil for Thou art with me. Thy rod and Thy staff they comfort me' Psalm 23.v 4,

to these beliefs of an existentialist, White (1977):

> 'I believe that man must learn to live without those consolations called religious, which his own intelligence must by now have told him belong to the childhood of the race. Philosophy can really give us nothing either - the quest for meaning isforedoomed. Human life means nothing'. (P. 105)
When there is less universal meaning to life than in previous centuries (Aries, 1981), and less overt sharing of those which exist, then it is difficult in the presence of deep pain to know how to comfort another in terms of philosophy. Pertinent to this situation is the lack of ritualised behaviours appropriate to situations of loss. This was found by Gorer (1965) to relate to the social isolation of the bereaved. Without ritualised ways learned from childhood, it is difficult to know how to behave on fraught occasions when feelings are intense; for without legitimised expression feelings are held back for fear that they might break out too intensely. In everyday interaction people often do not know how to express their feelings or what would be acceptable and thus engage in avoidance behaviour - verbal communication is inadequate for the situation.

When there is an embarrassing lack of verbal language then there may be a withdrawal of the non-verbal. General social tactics are used by people to avoid painful situations. Glaser and Strauss (1965), Webster (1981) and Maguire (1985) have studied these in relation to how professionals avoid distressing contacts with dying patients. All three studies found a withdrawal of proximity with excuses made to be elsewhere, avoidance of words directly related to the painful topic, failure to enquire about feelings, and outright denial. These methods were accompanied by failure to make eye contact and lack of facial expression discouraging the responses of the other. Alternatively there was the jollying, smiling approach which denied the seriousness of the situation and also left no room for reply. Individuals faced with this barrage of tactics become truly isolated in their misery.
Insufficient Basis for Sharing

Sharing is perhaps the key word in friendship; it usually begins with some mutual interest and people come to feel that they have some affinity with each other. Thus people sharing the same work, hobby, or love of something may become friends. As someone becomes severely ill and unable to partake in various activities there may be less to share in the way of interests, and friends may feel sensitive about happily discussing what was once shared, for this may emphasise the sense of loss for the sufferer. The ill person moreover, may not seem to be the same person that he or she was before the illness was diagnosed, there may have been changes in physical appearance and personality (Bloch, 1980); values and aims in life may have changed with knowledge of likely prognosis (Watson, 1984). In all these circumstances the old familiar base for communication has become steadily eroded.

A major barrier in communication has been found to occur when there is no shared basis for talking about the illness. Family, friend and patient frequently have different understandings of its nature and prognosis. The whole truth is often withheld from the patient (Lamerton, 1978). When this is the case and there are different levels of awareness (Glaser and Strauss, 1965), the patient and family cannot grieve together even if they would like to. Their responses are out of step. Whether the patient is unaware, or aware and hiding his awareness from the family, the situation is likely to be one of intense strain. When this happens, family and friends feel uneasy about talking too closely about the illness, or anything else, lest in their anxiety to avoid the topic they run straight into it. Stedeford (1984) interviewed 41 couples facing the
prospect of separation by death, and noted how the nature and prognosis of the illness had been discussed. She concluded that considerable suffering is caused by lack of acknowledgement of the illness situation, and this prevented the sharing of feelings. She felt that most of this was avoidable.

Inappropriate Emotional Climate

An emotional climate appropriate to the maintenance of sharing is not easily achieved in the long, often drawn-out stress of caring for, or relating to, a dying person. There is the physical exhaustion of caring or of continual visiting. The patient’s emotional responses to the situation - denial, anger, depression, bargaining (Kubler-Ross, 1970; Glaser and Strauss, 1965; Weisman, 1972), are not easy to confront, especially when family and friends are faced with the same adaptive process within themselves. They may find themselves out of step with the sick person and with each other. It is a time of mutual distress for patient and family have a multitude of negative and fluctuating emotions, which they must try to cope with in themselves and in each other. Recording the stress of this situation Katherine Ryan (1979) writes of her husband, who has already been quoted in this chapter. (Husband and wife were unbeknown to each other writing an account of the situation each from their own perspective):

'It was impossible to guess what his mood might be. If his spirits were low then I would have to make my own appear far brighter and more optimistic than they indeed were'. (P. 90)
Some people cannot stand the long strain, and Ryan writes, though not of his wife:

'The real problem with having cancer is that people get tired of waiting for you to die' (P. 351).

Not surprisingly, family members have mixed emotions which they find distressing; they have love and concern for the sick person but also anger and resentment for the impact of the illness on themselves, and sometimes aversion to the physical effects of the disease and its treatment (Dyk and Sutherland, 1956). Tension rises with stress and however loving the family, there are outbursts of emotion (Aitken-Swan, 1959). Families try hard to hold back their feelings but worry about being able to do so (Parkes, 1972). These conditions produce a very poor climate for the mutual support that is part of love and belonging especially when feelings of guilt are added to the existing trauma. When all these communication problems are considered it is not so hard to understand how loved people may become socially dead before being biologically so.

However, whilst an exploration of the problems of communication offers some explanation for the social isolation of dying people, it does not account fully for the rapid deterioration in relationships that sometimes occurs (Clement-Jones, 1986; Wortman and Dunkel-Schetter, 1979). Here the symbolic interactionist approach brings insights in its focus on the dynamic nature of human interaction, with its elements of response and counter-response. When Goffman (1963:5-6) describes social reaction to
those with an undesirable trait he describes the subsequent defensive response of the stigmatised individual. This in turn is perceived as 'a direct expression of the defect', thus the isolation grows apace in the negative chain of response.

Wortman and Dunkel-Schetter (1979) took a symbolic interactionist stance in examining the break-down of relationships around the cancer patient - they focused on the dynamic process within the interaction. The patient facing a diagnosis of cancer is filled with anxiety and has very negative feelings about his situation. He has a real need to clarify his thought with others if he is not to feel unreasonable or abnormal. Others have the same negative approach and could share and affirm him, but for the belief that it is harmful to do so. They believe that whatever their true feelings they should remain cheerful, optimistic and positive. This conflict within 'others' results in avoidance of the patient or at least of the subject he so wishes to share. The patient interprets this response as rejection, and then at a time when help is most needed, may in anger at this perceived rejection, exaggerate difficulties, demand attention, or withdraw, increasing the gap between himself and others. Thus a spiral of deteriorating relationships begins.

This kind of deterioration of relationships may occur around the patient in an institution. Strauss and Glaser's (1977) sensitive study of the last weeks of the life of the unpopular hospital patient, 'Mrs Abel', is a poignant illustration of this situation. Jory Graham (1983), a journalist and cancer patient, gives an account of her personal angry
response to perceived professional insensitivity, and then comments generally:

'We all know cancer patients, healed or struggling with metastatic cancer, who are so chronically depressed that we cannot bear to be with them. Until now their depression has been attributed to the paralysing terror of cancer itself, or to depression that effectcd their personalities years before cancer ever occurred. But my readers furnish ample testimony to the crushing effects of doctor's cool medical detachment from patients. For every superb physician who has no trouble making contact with his patients, there is apparently a counterpart who can treat only the disease, not the person who has the disease'. (P. 51)

The spiral of withdrawal and counter-withdrawal, whether it be with family, friend, or professional, provides very little basis for open communication or for the type of warm relationship considered to be so important to dying people.

RESEARCH DATA - DIMINISHED RELATIONSHIPS AND DIMINISHED QUALITY OF LIFE

There was much evidence in the data to link the experience of feeling cut-off from warm relationships, with low quality of life, so low that it sometimes resulted in the feeling that life was not worth living. The reasons for this isolation were: being institutionalised; the absence of significant others through distance and death; and the effects of the disease.
Separation from Family

Seven patients spoke poignantly about being institutionalised. It was not that any of them complained of the care that they received, but rather that they experienced an acute feeling of loss in being separated from home and family. To them, quality of life meant a return to those they loved. For example:

Mr PA (Hospital) who had recently married: 'To get home to my wife. My love of my life, my wife. I give myself another fortnight - a little girl (wife) is waiting for me - we will be together at six o'clock. You see her - she is beautiful - I worship her. Come again'. (He reached out and held my hand - his eyes filled with tears.) (First response)

Mr S (Hospice): 'To get home - my number one priority - get your priorities right they say - I have the best wife and family at home'. (First response).

Mr A (Hospice) indicated the negative weighting effect of separation from home in his quality of life measure. As discussed in chapters 6 and 7 he had experienced very severe pain, which had now been controlled, and this had made him a 'happy man', but he missed being with his family. He spoke of the positives and negatives in this evaluation:
FEELINGS ABOUT QUALITY OF LIFE AT PRESENT

Delighted X Terrible

Pain Control Being away from home

Food

General Attitudes

None of these patients went home; all died in the institution. There was some direct evidence of the physical and emotional toll illness such as this takes in the home, particularly in the case of elderly couples, both of whom are frail. It led to break-down in the following two instances:

Mrs T (Hospice): 'I do worry about myself - my husband and me both together in the house - in the end it got my husband down - he is in a home - we got to the end, we couldn't bother to speak to each other'.

Mrs G (Hospice): 'Keeping Fred well, he has taken the blight of this - he is not keeping at all well, that is why I am in here. I had to come in because I could see Fred breaking up and where would I be then. Fred has done all the housework, he has always been waited on hand and foot. When I started being ill he had to learn by dribs and drabs - has taught himself, he has done quite well'.
The Absence of Significant Others.

People who were significant to the ill person were absent because of death or distance, the former was not surprising in samples of older people (58% of the hospice ‘random’ sample were aged 70 and over and 73% of the hospital sample). Another reason given for being cut-off from family and friends was that they could not cope with the emotional impact of the illness. The result of these circumstances was that considerable proportions of respondents expressed a sense of social isolation; 13 (25%) in the hospice ‘random’ sample and 10 (45%) in the hospital. At a time when they most needed to share, to have, and to give love and support, there was no-one. There was often a feeling of acute loneliness. Mrs PO (Hospital) expressed this as the loss of sharing:

‘Loneliness is a big thing ... if my husband were alive I could say to him, “Look at that beautiful blossom”‘.

Mrs PF (Hospital) was the last of her generation. She said:

‘All my friends have gone before me; a few weeks ago I wished someone would finish me off ... when you get left and have no-one of your own this is what upsets people’.

Others were separated from family and friends by distance, as well as by their busy lives. For example:

Mrs PJ (Hospital), ‘I don’t see many people. My daughter is a school teacher and her time is limited. The other two daughters live
(overseas), this is when I miss them so much - of course they communicate and rang my doctor. The sad thing is why they ever went there. I am going to say it'.

The perception of two others was that loneliness was associated with social change. Mrs PI (Hospital) felt it was a change in attitudes:

'A lot of the trouble of today is with the youngsters - when you go to talk to someone they are not listening to you - ready to come in with their point of view - all me, me, me - a bit selfish - no-one has time to listen to anyone else. No-one has time for the old people - perhaps it is dawning on me that I will be old and need someone to care for me - and the attitude will not be there. No-one looks up and says thank you - shops - restaurants - that is what I am hooked on at the moment - this appreciation lark'.

For Mrs O (Hospice) it was changes in her neighbourhood:

'Quality of life? Things are not the same - neighbours and friends are not the same ... I am the only white (left) - others are coloured'. (First response).

The Attitudes of Others to Cancer and Dying

The fear surrounding cancer and dying had created social barriers for others; they felt isolated because friends and acquaintances did not know how to approach them or what to say because of their own pain and fear.
Mrs L (Hospice) was explicit. She has already suffered multiple loss through death in the family and the additional loss of friends and acquaintances had become 'the last straw'. In her description it is possible to recognise the spiral of response and defensive counter response that resulted in such deterioration of relationships:

'What is important to your quality of life today?' 'Nothing any more - in my predicament to make it short and sweet - as short as possible with the least pain ... I haven't got anything any more - no husband, no children - life has so deteriorated over the years, people have deteriorated ... Friends, they don't want to talk any more. It all started off with the neighbours four years ago. I became riddled and the neighbourhood, they didn't know what to say. Not that I am bitter, I make a joke of everything. For example, I have had a nurse once a week to give me a bath. When my tummy starts rumbling I say, "Mother Cancer has got some young ones". They know me and think I am very funny and silly.'

Running like a thread throughout this data is the pain of communicating about the illness and its likely outcome. To this difficult situation people bring the traumas and problems that already exist in their lives and which make it so hard to cope; their need to avoid or deny painfully cuts them off from the sick person; the sister of Miss E (Hospice) had already experienced one loss through cancer and she could not cope again:

'My sister doesn't think I am ill - a friend tried to tell her but couldn't get it past her. I feel she thinks there is nothing wrong.
I can't communicate - it is very important - I realise I am never going to get better. I have a friend who comes in nearly every day, my sister goes on holiday - it doesn't bother her but it would bother me if I were in her place.

Mrs PN (Hospital) with regard to her prognosis, 'sometimes you can talk to a stranger better than the family.'

The Impact of Severe Symptoms

Severe symptoms can act as a barrier to communication when patients feel too ill or tired to cope. Mrs GD (Hospice) had experienced this situation when she had undergone surgery and chemotherapy treatment in the hospital:

'When I was very ill I didn't see any of them (friends) - I was vomiting and didn't want anything ... I couldn't even thank people so felt out of life's stream'.

Various types of breakdown in relationship have been described in this section; whatever the cause they were characterised by diminishment or absence of communication and sharing with significant others, resulting in reduced quality of life, sometimes to the point when life no longer felt worth living.
WARM RELATIONSHIPS AND ENHANCED QUALITY OF LIFE

By contrast, the relationships that were spoken of as contributing to quality of life were marked by communication that contained elements of sharing and mutuality, giving as well as receiving.

Receiving and Sharing

For Mr R (Hospice), part of quality of life was the receiving of family support that was made possible by being able to acknowledge and share the seriousness of the illness:

'My kids came down and my sister to see me. They all know what is going on, so that is a support. You need support when you are ill. My Mum, she had cancer for seven years - we lived with it - she had to live downstairs - having Mum downstairs was our family life ... I was called when I was in Northern Ireland. You could look into her face and know she was going to die. You can, can't you. My brother came up and said, "You have got what Mum had, haven't you." I never thought I would.'

Support of various kinds, the giving of the self in time and effort, was a symbol of love and caring that affirmed the warmth of a relationship. For Mrs H (Hospice) it was the sacrifice of her son who had cared for her alongside a responsible job, that particularly mattered:

'My son he is the kindest boy, he looked after me for five weeks.'
Another aspect and measure of the giving of the self for her, and for others, was visiting. Being visited was spontaneously stated to be important by 15 (29%) of the hospice 'random' sample and 8 (36%) of the hospital. For example:

Mrs H (Hospice), 'It is quite a thrill having my friends and family to see me in the evenings.'

Mrs PE (Hospital), 'Visiting me - it shows someone cares for you - my father does not bother about me. My husband comes in every day.'

Mrs PL (Hospital), 'At least you know who your friends are - some don't come to see you.'

There was a particular delight in grand-children. For example:

Mr K (Hospice), 'My grandson he is wonderful. He will be here in the afternoon - it is school holidays.'

Quality of life enhancing communication could be of many kinds; a letter, phone call, bunch of flowers were all symbolic of warmth and caring.

Miss C (Hospice) 'I am friendly still with old work-mates. They sent me a huge bouquet of flowers.'
The potential of the letter was demonstrated by Mr F (Hospice) who marked his quality of life measure as 'near delighted' because of one he had received.

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The letter that had boosted his satisfaction so, was handed to me to read. It had four main elements - concern for him in his illness, reference to his useful life, belief that the hospice would care for him well, and information that his friends were praying for him. These elements so exactly mirrored those factors that Mr C had said were important to his quality of life that it demonstrated the unique support that can be given by close and concerned friends who know each others' needs.

The symbols of love and caring that have been discussed were frequently evaluated against the context within which they were given and the expectations that this engendered. Strength of caring was measured by the effort that had been put in appropriate to the situation.

Miss C (Hospice) 'A cousin and a niece came to see me yesterday - quite a long journey from Harrow and Hampstead.'

When distance or infirmity prohibited visiting, or when there were other accepted reasons to prevent personal contact expectations were reduced:
Mrs PO (Hospital), 'I have a large family who work for a living, so
accept that they will not all be here today.'

Mrs PK (Hospital), 'My sister-in-law (only relation and disabled)
rings up from (Essex) every day - she is trying to get a car
arranged for a visit. It would cost £100 for one day. I wouldn't ask
her to do it for she is only on a pension like me'.

Giving and Sharing

Up to this point the focus has been on the receiving of support by
respondents. However, there was considerable reference to their anxiety
for others, discussed in chapter 8, and to giving as well as receiving as
part of the warm supportive relationship. Giving to the other was
expressed as important by 15 (29%) of the hospice 'random' sample and 3
(14%) of the hospital. Concern for the other was often the first response
to the quality of life question and this was most marked with elderly
patients when the spouse was also frail. For example:

Mr K (Hospice), 'The most important thing is that my wife and myself
should get better. She has insulin twice a day and has arthritis.'
(First response).

Mr H (Hospice) 'Everything is alright at home -my wife is alright.'
(First response)

For many, their quality of life was wrapped up with the welfare of their
families. For example:
Mrs Q (Hospice), 'Quality of life - that my family won't have worries about me ... I am undecided if this illness goes on what I should do to make life easier for them.'

Mr C (Hospice), 'I worry about my wife - if she is alright so am I - if she is not then I am not.' (First interview).

'There is only one person that I worry about and she is all the world to me.' (Second interview).

Mr PF (Hospital) - a younger man, had remarried the previous year at a time when he had suffered a serious illness. He and his wife had agreed to marry when he was able to walk. The day previous to the interview he had learned that nothing more could be done to arrest the progress of his disease. His first concern was for her. He said:

'Coming to wake up tomorrow morning (tears) I had to tell the wife yesterday morning. I feel I owe her something - I can't do anything - she said just being here (mattered). I don't know how long I have got to be here - I didn't really think I would be here now.'

Concern was shown by making arrangements for the welfare of others:

Mr PB (Hospital), 'I have a handicapped sister - it is important that she will be cared for.'

Sorting out financial and material affairs:
Miss D (Hospice) 'I have a good friend and have left everything to her.'

Mrs GD (Hospice), 'I have given my car to my daughter and son - better to give now than for them to have to wait for me to pop off.'

Taking an interest in the lives of loved ones:

Mrs N (Hospice), 'My grandson's Bar Mitzvah, how do I know I will be here in a year's time. What prayers can I say?'

And making personal sacrifices on their behalf, trading one priority for another. It was important here to have choice and control in the situation:

Mrs R (Hospice), 'As long as I am laying here I am happy. I wanted to give my family a break.'

Mrs V (Hospice), 'It was my decision to come here because I knew what was going on ... I didn't want the children to have to worry.'

In the sharing and giving these respondents were often very far from the passive patient receiving the support of others. It was important to give as well as to receive.
CONCLUSIONS

The data in this section indicates that warm mutually supportive relationships with family and friend were of fundamental importance to a large proportion of the sample. When they did not exist then quality of life was severely diminished, when they did it was enhanced and relationships could act as a support and a defence against despair: heavily weighting the quality of life equation towards the positive. Mrs PK (Hospital):

'I sit in a chair and look around and say to myself, "Well, I have friends, can cope with money, have a roof over my head - what more can I ask for - you think of all the friends you have got.'
CHAPTER 13 - WARM RELATIONSHIPS AND THE PROVISION OF CARE

This chapter explores the importance to the quality of life of respondents, of the facilitating of warm relationships with family and friends by staff; it also explores the importance of developing warm relationships and a sense of belonging in the institution. A group of nine patients in the hospice were able to talk of the institution as 'family' and 'home' because of the warmth and welcome that they experienced there.

The great yearning of some respondents to go home was noted in chapter 12. This suggests that one aim in care should be, whenever possible, to pave the way for this to happen; but this may not be possible if the family do not want this or cannot cope and, as has been seen in chapter 12, sometimes the patient chooses to be away from home. The experience of Mrs GD (Hospice) is a warning not to take for granted that everyone would prefer to be at home. She expressed herself forcefully on this issue for the pressure in her previous hospital to get her home had done much to destroy her quality of life. She felt it would be all too much for her husband:

'What worried me about going home was that the bowels cannot be adequately dealt with - my husband putting me on the bed-pan and clearing it up. Now it is not a factor here because it is adequately dealt with - not a worry at all. All this pressure to get me home - made my husband feel a failure. I should have turned to them and
said this is an impossibility - I didn’t have the strength - was totally paralysed - can’t think why I couldn’t do it or someone couldn’t see it. I put a bit of the load of that on the nursing staff - they knew I was vomiting and couldn’t do exercises in therapy - it must be happening to other people.’

It greatly added to her quality of life to know that her husband was freed from the burden of caring, and with encouragement was able to enjoy life:

‘(Chaplaincy) she is marvellous - my husband has even gone to her. She has manipulated him into enjoying life - going out for a meal - theatre. We had a highly social life. He stopped, said he hadn’t got time’.

This chapter therefore centres around the need for warm relationships for those who, for whatever reason, need to be cared for in the institution. The response suggests that two aims of care are important to quality of life:

1. Maintaining warm supportive relationships between the patient and family and friends.
2. Facilitating warm relationships in the institution
MAINTAINING WARM SUPPORTIVE RELATIONSHIPS BETWEEN PATIENT AND FAMILY AND FRIEND

One issue in maintaining contact with family and friends is the distance that they may have to travel to visit – sometimes people are moved away from their own familiar hospital and town to receive terminal care elsewhere. Some of the greatest sense of helplessness and unhappiness came from two patients in the hospital who understood that they were no longer fit to live at home and would have to be moved somewhere else. This is a real problem particularly for the elderly whose friends may not be able to travel far. Mrs PG (Hospital) had just learnt of her prognosis.

'It comes as a shock, I don't know how long I have got ... I am concerned about being moved to ... my friends are all (here). I suppose they will decide tomorrow what they will do with me.'

One means of retaining maximum home contact was through week-end visits. This would, for example, enable a husband who had to work in the week, to care for his wife at the week-end. Adequate symptom control, transport and home arrangements were important if this was to be successful. For Mrs I (Hospice) who was offered a choice this was a difficult decision because she needed constant skilled nursing attention to keep her comfortable:

'I do have help at home in plenty ... and in this case there is the fact that this is a hospice and not a hospital and I have been given the option of choosing for myself - go home weekends - days'.
The most usual means of maintaining contact was through visiting, which as discussed in chapter 12, was very important to many people. For example:

Mr PE (Hospital), 'Children and my wife - thinking about them and being able to have contact with them - visiting hours.'

However, visiting does not always provide the facilities for the deep sharing that is sometimes needed. There is very little privacy in a ward:

Mrs GD (Hospice) 'With visitors - my mother is very deaf - anything of the least importance has to be said for everyone - B (the social worker) said I could use her office. You listen to other people's conversations ... the other day my daughter was in a bit of a two and eight and I am sure the person opposite was listening from what she said afterwards. Visitors find it difficult - single rooms are not ideal either'. (Because of the loneliness).

Patients who were ambulant could often find corners in the hospice or hospital away from the wards but for those who were confined to bed, relationships could be restricted. This would suggest that it might be helpful to have rooms into which beds could be wheeled whenever families needed to be in private. However the existence of this provision would need to be made known to families on admission for it would hardly be in their expectations.
Some visiting was not helpful however; Mrs R (Hospice) who was very weak and only able to talk for a few minutes at a time said:

'My sister’s visits do not cheer - I just want to rest - am always tired. As it’s quiet here like this I like it - I like to be on my own.'

Maintenance of family contact may at times mean encouraging the family to understand how important is their non-verbal communication - to sit with - to hold a hand - to leave alone at times - to allow to sleep; thus freeing from a compulsion to talk.

Another important time for being present with the patient was around the time of death. The hospice built a flatlet to enable a relative to stay overnight. However, this was not used as much as it might have been for while the flatlet was in a building adjacent to the hospice and had a phone, relatives often wished to be nearer to the patient and preferred to make themselves as comfortable as possible in an armchair beside the bed. Here respecting the choice of individuals was important.

The facilitation of contact by phone also contributed to quality of life; references were made by three patients in the hospital, all in different wards. For example:

Mrs PK (Hospital), 'My sister in-law rings up every day - one day they let me go to the office and answer the phone - that was kind wasn’t it - my sister-in-law is getting on and can’t visit.'
Mrs PE (Hospital), 'You always get the message if someone rings from home.'

The inference was that this was almost beyond expectations in the busy ward. Although the hospice offered the same service there was no reference there.

These references illustrate the importance of maintaining warm relationships through visiting and other forms of contact. Research with seriously ill people and their relatives (Hampe, 1975; Pottle, 1990) indicates that this is an important aim in care, for stress levels are reduced for both patient and family, when visiting is encouraged and the family are permitted to help in whatever way they can.

FACILITATING WARM RELATIONSHIPS IN THE INSTITUTION

Another section of comment related to the importance to quality of life of warm relationships with people in the institution. One of the surprises in the research was the extent to which patients sought love and belonging there. Friendship and belonging statements were made by 14 (27%) of the hospice 'random' sample, and friendship only statements made by 3 (14%) of the hospital sample. Women expressed the importance of friendship and belonging more than men; in the hospice sample 40% of women compared with 9% of men.

The Search for Friendship in the Institution

The key concepts here were 'loneliness', 'friendship', sharing', 'mutuality' and 'love'. There was evidence that patients could come into
care already very lonely seeking to fill a void. Mrs L (Hospice) was an example; as noted in chapter 12 she felt greatly deprived of love and belonging at home. She had investigated another institution before deciding where she wanted to be, and said of this:

'First I had a look at A and then here. I chose here - why? - down in reception the Sister showed me round and such a warmth came from her - here you are met as a person. You are received. The first impression is usually the right one.'

It was possible to be extremely lonely although surrounded by people in the ward. Three of the hospice 'random' sample and five of the hospital sample talked directly of loneliness in the ward. Mrs N (Hospice) used to wander around the hospice looking for company:

'It is more the loneliness than anything else - it does not seem so bad when people talk to you, but when they go (leave) you feel right down in the dumps.'

Mrs PO (Hospital) said, 'What matters to me is that I can keep my head above water, have visitors and not too much loneliness ... putting friendship first applies to the hospital as well. There is nothing worse than to lay here and have no soul to say hello - to watch the clock go by - I used to put my head under the bedclothes because I felt no-one loved me, but I have learnt different since.'
Friendship in the Institution

The friendship of fellow patients was important to several people. Mrs D (Hospice) had enjoyed a friendship with the patient opposite, who at the time of interview was unconscious and obviously in the last hours of her life. They had found that verbal communication was not absolutely essential when there were other factors to bind - a sense of affinity transcended the difficulties. Mrs D kept glancing over to her and said:

'I have been so fond of that lady and goodness knows we couldn't communicate. I am a bit deaf and yet what we said was through a thick veil of tongue and teeth. If my husband were here she would point until she had what she wanted and not give up. I admire not giving up. Sometimes people do not bother and give her the wrong thing. As a sticker she was it. It is almost an insult to speak of her in the past tense. God bless her.'

The Chaplaincy Department of both hospice and hospital appeared to excel in offering friendship that was characterised by warmth, and the sharing of interest and humour. It was quality rather than quantity that mattered. Mrs PO mentioned above, 'had learnt different since' because of the weekly visit of a member of the chaplaincy staff:

'She (X of Chaplaincy department) came to visit me - I only have ten to fifteen minutes with her but in that ten minutes we have such a laugh - I can make a joke out of nothing.'
Mr T (Hospice) appeared to be alone in the world, the basis of his friendship with the chaplain was a shared hobby:

'Y has given me this watch and is bringing a clock for my locker - there are some that you do not have to wind up.' (His eyes lit up as he said this).

Another member of the chaplaincy department became a friend of Mrs F, who being a friendly person had made many warm relationships but she yearned for one that had real depth. Once more this was based on weekly visits. Mrs F saw this friendship as:

'God's answer to my need of a real friend.'

The same member of the chaplaincy team also became a friend to Mrs D (Hospice). What was most appreciated by Mrs D at one interview was her willingness to share a little of her own vulnerability, for when people can relax in each other's presence without the continual need to 'keep face' then this is a sign of real belonging. Mrs D was visited after her friend had been away for a week-end

'She looked as if she had had the daylights bashed out of her. I suspect that she was brought to realise things that came very hard for her. I had the feeling that she was more than usually moved and I was glad to see her in that state, because she is usually so smooth, smooth, smooth, calm and blessed. Something more has happened to her now and I doubt if from this time she will ever be
quite the same. Of how many people can that be said. If she wants to
tell me she will. I shall not ask. I admire her more than I can say
- in fact of all people outside my immediate family, I would say I
loved her'.

This response and the general observation of friendships with staff and
other patients indicates that, given the opportunity, it was possible to
make warm relationships right at the end of life. However, it is not
always easy to make friends, many people have natural or cultural
diffidences:

Mrs F (Hospice), 'People here need social contact - I was talking to
a patient this morning - English people are not very willing to talk
to strangers.'

And, certain organisational factors were seen to enhance or diminish the
opportunity. The first thing that helped was a general friendly
atmosphere:

Mrs PN (Hospital), 'Friendly ... a happy atmosphere. That's what you
need in a hospital.'

It was seen to be the province of management at different levels to set
the tone. For Mr PE (Hospital) it was having a sister who could create a
happy atmosphere and permit movement about the ward:
'You can walk up and down the ward, speak to other patients ... they help you as you help them. Most important is having a sister who will allow you do it ... if you have a nice sister you have nice easy nurses.'

Mrs GD (Hospice), 'I don't think I actually mentioned the nuns - make the whole difference to the place ... whole standards would drop (without them) - the atmosphere - the warmth - the welcoming - when you have worked in a hospital you know the difference, although you try to be kind ... the atmosphere you find immediately - it's not just me - every visitor who enters the place - to do with their prayer life - their peacefulness - their happiness - we have enormous laughs - a delightful sense of humour.'

The size of ward had some influence on the opportunity to make friends; in a large ward there is more likelihood of finding someone else who is communicative and compatible. Mrs N (Hospice) had been transferred from a large acute ward of a hospital to a small bay of the hospice; she did not like the change, since as has already been stated she felt acutely lonely. In the hospice bays it was quite possible to be surrounded by others who were too ill to talk or could not communicate for other reasons, but to have kept moving patients about as they deteriorated would have been unsettling for all concerned:

'A nasty shock - I have no way of holding a conversation. I feel not exactly pushed out, the nurses do their best to keep you bright but they cannot be with you all the time. What do you think would help ?
In X (previous hospital) there were twenty beds - always something going on. You want more life.'

Mrs F (Hospice), 'Someone to talk to, there is not always someone, the adjoining patients are not very communicative; (of the three others in the bay) one is deaf, one is withdrawn and the other is confused.'

Mrs I (Hospice), 'The great age gaps in the ward between you and other people.'

Mrs N would have benefited from the leisure centre that was built after her stay, as did Mrs F, at least for as long as she was able to go there in a wheel-chair.

In the hospital a busy ward situation and lack of stability of contact with nurses could reduce the basis for the development of warm relationships with staff. The hospice did not have to move its staff about for training purposes:

Mrs PH (Hospital), 'They don't have time to talk to you - it was dreadful yesterday, the nurses never stopped running - they haven't got time to talk to you.'

Mrs PK (Hospital), 'They change the nurses too much - the nurse doesn't get to know the patients.'
When Mrs N was able to begin to develop some relationship with the nurses it made a big difference to her quality of life:

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'It made a world of difference, the nurses have talked with me - daughter came up and son tonight - if it could be like that I wouldn't mind.'

Response such as this suggests that systems such as primary nursing, in which each patient is made the responsibility of a small team of nurses, would enable better relationships to be built up between patient and nurse than in a task oriented approach when the total care of the patient is not related specifically to any nurse.

The Institution as Home and Family

Another form of warm relationship was seen in the comments of nine patients who indicated that the hospice provided for them a sense of family belonging. This was particularly important to their quality of life. The concepts used were, 'family', 'belonging', 'permanence', 'feeling wanted', 'home', 'love', and 'care'; those associated with a nurturing family. For example, Mrs A (Hospice) said:

'I am a person who has lived alone - am 83 - now a new life is beginning for me because I am amongst people who care - they look after you like a family. I have never had a family.'
None of the hospital patients spoke of the hospital as home, and this is not surprising since there is not the expectation of permanency in acute wards, for if the disease is thought to have a long chronic stage and the patient cannot go home, then arrangements are usually made for transfer elsewhere. It was noticeable too that none of the hospice patients whose comments focused mainly and positively on their own home and family, spoke of the hospice in this way.

There were certain characteristics in the situation of these nine, (seven of whom were women), with an age range of from 53 to 83 years, that were likely to have influenced the perception of the institution as home.

1. All could no longer manage to look after themselves and had no family member or friend able to look after them. All but one lived on their own, and all had accepted to some extent that they were never going to get better. They were conscious therefore of a void of care and belonging that needed to be filled. For example, Miss E (Hospice) lived alone, and as previously discussed could not communicate with her sister. She said:

   'I feel that I belong here - I do feel that I belong here ... I realise I am never going to get better.'

Miss LD (Hospice) lived on her own and had never had a family. She said, 'This is my home.'

2. They had all been invited to think of the hospice as home and family, and assurance of the permanency of arrangement was important.
Mr O (Hospice) had said to a nurse:

'I know I am in here for good - this is my home now. Can they ever throw me out?'

Mrs F (Hospice) felt a bit guilty because she was able to go out and about and spend the odd week-end away and yet was taking up a bed - she was benefiting from symptom control. She discussed this with the doctor:

'I said to the doctor I shouldn't be taking up one of your beds. He said, "You can make this your base."

3. They had all found that factors in the hospice care were acceptable to them as individuals; an invitation may be offered but for it to be deeply accepted it has to be acceptable. These factors were a quality of care and interaction:

Mrs E (Hospice) 'Someone looking after me - being looked after in a hospital like this you would want it to go on. How? Supposing you were young and mother was around, that is the kind of looking after that you want.' (First response).

Mrs F (Hospice) 'This place is full of love and caring - (that is) - having time for you - people think it is important.'
For Mrs S it was also an association with her roots:

'If you feel someone cares. Having the nurses - when you live on your own it is very hard. I thank God for them every night - they talk to me and look after me ... it's being here that matters. Now I have everything that I want - I feel really wanted. They have taken me in permanently. I wanted to be associated with Irish people (comes from Eire). I have been a widow for many years.'

For some people their own expectations of family belonging were ones of mutuality of giving and they took this very seriously. Mrs CD (Hospice) said:

'We have an old lady I feel very sorry for. She has no family and we say, "We are your family". She says, "Kiss me" and I can't get near enough. She is not a loveable character so nurses do not respond in this way. You see all this agony going on in this unloved lady. Some nurses do naturally show affection, it is the young girls ... I get very involved with the family life, the patients don't know if it is a good idea. It adds to the quality if you can contribute something.'
The Beginning of Friendship and Belonging

The time of admission to any institution is a very impressionable one - when what is said and done is likely to create a lasting impression and set the tone of relationships. The hospice had a special welcome likened to that which is often given to a guest arriving at home. When a patient was known to have arrived the ward was contacted and a senior member of staff, usually the sister, dropped what they were doing and went down to the front door or outside to the ambulance, often taking another member of staff with her. The patient and family were then greeted and conducted to the ward. Here they were introduced to others and to the area appropriate to their use; a tray of tea was provided. This is a powerfully symbolic way of conveying welcome and is practised in various ways in hospices. It has an impact at time of great vulnerability and has been described by West (1976) as being a returning point from isolation back through open awareness to communication and acceptance.

This welcome had a strong effect on one grieving man. Mr B had returned home from hospital after his rapidly advancing cancer had been diagnosed; he had been expecting to stay at home. It had come as a shock the next day to find his G.P discussing the future with his wife and to learn that it was proposed that he should be immediately transferred to the hospice. Three days later he was included in this research. His response was:

'The very welcome here - it seemed different - you usually walk in and are a number - not here. I thought it was wonderful - it was the pleasant atmosphere and everything. At X (previous hospital) they would help you - but the atmosphere is different. They (the hospice)
look after your comfort - you are one of the family - nothing is too much for them. They call you by your Christian name - the doctor said he wanted to be known as Doctor David.'

Here the welcome, which is not a 'set form' was tailored to the individual - a void needed to be filled and an invitation was being accepted because it was being found acceptable.

The Growth of Friendship and Belonging

The soil of friendship and belonging was in the cycles of interaction that took place - growth has to have something upon which to feed - the nutrients that emerged were, affirmation of belonging, natural spontaneous sharing, mutual affirmation of relationships and:

Affirmation of belonging Affirmation of belonging helped to settle one disturbed patient. Mrs F (Hospice) was talking of another patient, and said:

'She has been in a couple of days - was a terror the first night - kept going on about her husband - the nursing auxiliary - a lovely girl - she said to her "You are one of us."'

Natural spontaneous sharing This was a natural human sharing of feelings and interests, not contrived in any way - based on companionship. Mrs GD (Hospice) said:
'I enjoy the company of the nurses because they are spread over a wide range - enjoy the young gossip, though not their homesickness - the middle aged, like me - the nurses come and talk about these things. The staff nurses a different breed - it's the quality of girl - their training and intelligence - they bring another element - they talk on a different level - theatres and books. So you have got all life coming in even if you are not going out. They all contribute something to my life. It gives a family feeling - they don't mind sharing their lives with me ... I was an X ... That has stopped and this is my life - you can't go back - so here is an extended family'.

Mrs F (Hospice) had a great sense of fun and this was shared. She said:

'The nurses they tease. I get up in the night to go to the lavatory and when I come back I find they have dressed up my pillow to look like someone in the bed.'

Personal sharing is symbolic of a degree of belonging. This had delighted Mrs F (Hospice) for she had an opportunity to go on a coach drive but had no shoes as she had been admitted in her slippers. It had mattered very much to her that one of the nurses had offered her a pair:

'I said I couldn't go because I have no shoes - came in slippers. The nurse said, "You can borrow mine."'
Mutual Affirmation of Relationship Being warmly greeted on return from an outing, was symbolic for Mrs F (Hospice) of belonging. One afternoon she was taken out to a nearby park in a wheel-chair. The pleasure she obtained from this outing was derived as much from the welcome she received on return as from the outing itself,

‘Listening to the band, having a cup of tea, being caught in the rain and seeing the nurses looking from the window, and being able to wave to them’.

At a later interview Mrs F had become much weaker and realised that she would soon be in bed. She questioned the nurse as to what this would be like. It was well known that she had a handicapped daughter who could not care for her. The nurse’s reply sensitively reflected this situation, greatly contributing to her quality of life. The nurse said,

‘You are my adopted mother and when you need to be in bed all the time I shall look after you like a daughter.’

In this and other instances the aim of the hospice to provide acceptable family life had emerged in the natural interaction between its staff (many were young nursing auxiliaries) and patients.
The Problems of Warm Relationship and Belonging in the Institution

One problem that emerged with regard to the sense of belonging in the hospice centred around the expectations associated with home for there was a discrepancy between these and aspects of living in the institution - there was little space for personal possessions, or privacy from an outside world - personal space. Mrs GD (Hospice) said,

'The wards seemed very cramped - now don’t notice it - that’s my home now - lack of storage space is a problem, particularly for those people who haven’t got a family to take things home for them. It upsets me to see others, who have given up their homes trying to keep things in a little box - the cleaner gets aggravated. Lack of storage space is a minus for quality of life.'

'Lack of personal privacy - you can never really be alone - it’s like being in a goldfish bowl. You may want to read a book on your own - someone will come along and have a chat. I used to go in the garden and people would come along and say, “Are you alright?”'

Miss LD (Hospice), ‘This place is very important to me because this is my home - I regard it as my possession - am very territorial - I would like to have a door to shut - you can’t knock on a curtain.’ (First response).
Mrs GD made the only reference to a member of staff being perceived as intrusive. She said:

'X hasn't got from me what is wanted, our inner mind, which I am still hiding away.'

Warm people can be viewed by others as those who will share burdens. When families are so much included in the welcoming atmosphere then they can also intrude into the space of others. Mrs GD (Hospice) continued with some observations:

'Sister is very supportive as regards visitors - knows exactly what is going on. I have had trouble at night with relatives sitting with dying patients. They will talk to me in the night, so now I have the curtains pulled around. Someone woke me to tell me about rows in the family as to whether their mother should have been brought here. One said, "My bunions are killing me, I have to take my shoes off."'

Friendship and family belonging in an institution for the dying can bring difficulties that are not present in most natural families. It is not a normal experience to face repeated bereavement to the extent that it happens in a hospice:

Miss ID (Hospice), 'The terrible drawback of making friends and having them die in front of you. I don't like it but it has to be faced.'
The burden of loss can, unintentionally, be extended when grieving families return to the place where they have found comfort:

Mrs GD (Hospice), 'I can't take on this bereavement - wife of someone who died here was coming every week - so I acquired a little job - don't know if I shall pull back - become so involved. When someone dies I never feel sorry for them - it's the relatives.'

A sense of family for this patient also included her involvement in the grief of nurses who were part of that family - this did not however come over as if it was a burden to her:

'One of the nurses is going to get very hurt when someone goes - everyone is very aware of it and we shall all have to support her.'

This perceptive comment indicates the dilemma of nurses, for more than any other carer they are in close contact with patients, and suffer repeated loss. If we are asking nurses (and others) to give of themselves in friendship to dying patients, then we must be prepared to give support. The stress of this situation is indicated in the experience of Feigenberg (1980), a psychologist, who engaged in 'friendship contracts' with patients and found that the support of family and friends outside of work was very important and that it was not possible to offer this contract to more than five patients at a time.
There was a network of support in the hospice which was mainly informal, one nurse to the other (Malone, 1989). One of the medical students interviewed (Appendix 5) made this observation:

(Student A), 'There is a lot of talking - chatting between nurses and getting rid of their feelings - it is the most important thing for coping with the stress - there is a good communication between the nurses and the family who are left - the family can come back and chat - a sharing of sadness.'

Mrs GD and Miss LD were both admitted as much for social reasons as for the continual nursing care that they required; they both lived for some time after the interview, and Miss LD died suddenly while she was still able to be fairly mobile. The researcher felt from the above responses that some of the traumas would have been avoided if they had been able to be supported in some type of half-way house situation, that could provide more privacy and protection from a situation of the continuous death of others, until they required more nursing; but then the sense of family that had meant so much would not have been there in the same way at the end of life.
Despite some of the problems, a sense of family belonging greatly enhanced the last days of those patients who viewed the hospice in this way. It filled a void of belonging. As noted at the beginning of this chapter Mrs GD had withdrawn into herself because of the shock of her illness and the pressure in the hospital to get her home - it was the finding of an acceptable substitute home and family that boosted her quality of life. Her first comment of the interview was:

'I am very happy here but I can't find out why since I am disabled, cut-off from home' (she then proceeded to talk of the factors in her quality of life equation) ... I am very well-cared for ... food is very important ... the company of the nurses ... the family life ... visitors... (and the problems) ...lack of privacy ... lack of space ... the bereavement of others ... (and then a form of summary) ... when I came here I was emotionally and spiritually dead - this place has brought me alive - I can weep now. It wasn't for lack of trying by the hospital - they had a very good chaplain - it wasn't her fault, it was me holding on. The social worker used to come but was also going by the book - busy acute ward, then on own in side ward - isolated - but staff used to come in and I enjoyed them - I withdrew - the key that unlocks - more relaxed here.' (And by this she explained being offered a permanent home with a natural family atmosphere).
The potential for love and belonging in warm supportive relationships cannot be underestimated wherever it is found. Archbishop Bloom (1969) stated:

'People are much greater than we imagine and stronger than we imagine and when ... tragedy comes ... we see them so often grow to a stature that is far beyond anything we imagined. We must remember that people are capable of greatness, of courage, but not in isolation.' (P.1)

Miss LD, a younger person, found some of this courage and growth. She had always felt socially isolated and had suffered from agoraphobia. She said:

'It is important - very - that the people here are so loveable, it is the first time in my life that I have experienced uplifting love from one person to another. It's a pity that my life is drawn to an end and I have only just found it.'

CONCLUSIONS

The response in this section has indicated the very great importance of warm supportive relationships and a sense of belonging to the quality of life of these patients whether this was outside or within the institution. This supports the need for a major aim in care to be the maintenance and facilitation of family life, friendship, and belonging. There are several implications.
Organisation, Expertise, Qualities of Interaction?

Organisation, expertise and qualities of interaction; all have a fundamental part to play in enhancing the patient's quality of life through warm relationships. The organisation of flexible visits to home, institutional care near to home and family, and facilitated visiting and phone contact, help to keep the patient in touch with the family. Furthermore, friendship is facilitated within the institution between patient and other patients when it is easy to meet compatible others. It is suggested that friendships between patient and staff are more likely to arise when staff have time to develop relations, and when a system of care, such as primary nursing, provides for greater overall contact between patient and nurse in being centred around the individual rather than a series of tasks. If the aim is friendship then staff need emotional support when they experience loss.

Part of the organisation is the expertise that is provided - a team of professionals have been important in this section, the comfort and symptom control of a skilled nursing and medical team have enabled patients to engage in social contact, and their counselling and relationship skills plus those of social workers and clergy have assisted relationships within the family.

The qualities of interaction - the welcome, the reciprocity, the warmth, the empathy shown - has been a vital factor in developing and supporting warm relationships. Empathy - understanding of the situation of another - may be developed as part of expertise, but what stands out in this section is the importance of the natural warm sharing of humanity between
staff and patient; the term 'natural' was used several times. This does not depend upon any particular grading within any profession. Rather, it was the naturalness of people, especially the young, that was so important. This as much as anything else made it possible for the place of care to be viewed not just as an institution but as a place of friendship and belonging. For those who have lost their own home and who have little friendship or warmth in their lives, to live without this natural sharing, and mainly as part of a process of planning, assessment and evaluation must surely be most quality of life denying.
SECTION VII

QUALITY OF LIFE AND HAVING ACCEPTABLE IDENTITY
A further large section of response was centred around clusters of concepts that related to acceptable identity, acceptable that is to the self and others - 60% of the hospice 'random' sample and 68% of the hospital sample made some reference to this issue. In the case of acceptable identity they used the concepts of ability, dignity, worth, usefulness, strength, independence, freedom, control, status and role. Conversely unacceptable identity was associated with guilt, shame, embarrassment, low worth and being degraded.

Identity is defined as 'who or what a person or thing is' (Chambers, 1973:648); it is therefore an all encompassing concept with many aspects to which the labels acceptable or unacceptable can be applied. It is of course possible for one aspect of the person to be or feel acceptable and another not; the data are consistent with what is known of stigma (Goffman, 1963), that when the individual feels really demeaned in one area in life then the effect is global. Identity is above all a social concept since, as will be discussed, values by which the self is judged are learned within, and transmitted by, a social context.

Whilst there was much consensus in the samples as to the factors that made for acceptable identity, these had a differing importance for individuals. People came into the care situation with a variety of feelings about themselves and differing expectations. In addition many had been sensitised to issues of esteem by past care experiences. There is a comparatively large amount of data related to the negative, partly...
because the illness experience was so often one of loss of ability and partly because there had been some bad care experiences. Moreover to experience what is commensurate with expectations is often taken for granted, and therefore is not noteworthy but to experience that which is not, is. This section explores these issues.

BACKGROUND THE ILLNESS EXPERIENCE AND ACCEPTABLE IDENTITY

In defining acceptable identity or esteem of the self as a basic human need Maslow (1970) reviewed anthropological evidence and concluded that:

'Human beings are more alike than one would think at first' ... all people in our society (with a few pathological exceptions) have a need or desire for a stable firmly based, usually high evaluation of themselves, for self-respect, or self-esteem and for the esteem of others'. (P. 45)

It has become increasingly recognised in recent years that feelings of self-worth are important, and this is reflected in the use of esteem related concepts in quality of life assessments (e.g Padilla 1983). Feelings of self-worth are stated to be even more critical when dying (Krant 1974). Zuehlke and Watkins (1975) concluded from their investigation into the use of psychotherapy in terminal care, that patients had important psychological concerns, frequently involving questions and fears of an existential nature, such as feelings of depression, guilt and lack of meaning in life. The importance of self-esteem to the individual is that the measure of the worth of a person becomes part of that person's identity, as perceived by self and others.
When the sense of self-esteem is satisfactory then this leads to feelings of self-confidence, capability and of being useful and necessary in the world (Maslow 1970).

Theories of Self-Esteem - of Feeling Acceptable and Creditable.

Theories of self-esteem centre around the processes through which individuals assess their worth. Rogers (1951) sees the 'total personality' as comprising two overlapping circles, the one is self-concept and the other is experience. The interaction of the two represent self in relation to the environment. When there is an accurate matching between self concept and experience there is congruence. The experience circle of social interaction provides therefore, a series of templates, or sets of expectation, based on social norms and values that become internalised by the individual, and against which he assesses himself. When the result is satisfactory a feeling of self-worth is engendered, when less than satisfactory, various degrees of low self-esteem.

Becker (1973) views the organisation of social roles, rank and status, as a search for self-esteem. They give meaning to a life that will ultimately end, and are therefore man's response to death. If, as he states, they are a means of coming to terms with death, it might be expected that they would be of particular concern to dying persons, and that as individuals lose the part of identity that has provided this form of support, they might experience a greater need for other sources of esteem to fill the deficit.
A sense of self-esteem and worth may also be gained vicariously, or at second hand, throughout life, by identification with others who have status such as children or grandchildren who have 'done well', or by serving 'important others' or values important to the culture (Guttman 1977). Thus, for example, although an individual may have had to relinquish a role, whose prime quality is usefulness, it is still a matter of personal esteem that he or she identifies with such values.

Goffman (1963) takes an interactionist approach and identifies socially 'discreetable' aspects of the person that result in stigma or unacceptable social identity, one of these being 'abominations of the body - the various physical deformities' (p. 14). He then explores the ways in which 'others' may mediate a sense of low self-esteem to those who for any reason possess such an 'undesired differentness'. For example, an individual acquiring a stigmatising attribute, such as a handicap or chronic illness, may previously be high in self-esteem but in the process of subsequent interaction take to himself the lowered value that he perceives is given to him by the 'other'. In this situation he perceives that the other is comparing him with a wholeness template and finding him wanting. This perception may stem from embarrassed interaction, it may also stem from the perception that the 'other' associates him with a lower, or downgraded, template. It is frequently the case that those who are seen as different are expected to accept lesser life-styles and standards of living as a norm.

This 'differentness' may be further enlarged or emphasised through various mechanisms. There is a tendency for an individual who is
handicapped in any way, to be judged in terms of that handicap; for example someone with a physical handicap may also be accredited with mental disability; his handicap is seen in global terms. This experience is recognised as common in the title given to a media programme on handicap, as, 'Does he take sugar?'

Wright (1960) suggests that a mechanism of 'anormalisation' may occur when 'normal' individuals encounter the disabled, and experience a dissonance between their expectations and their actual perceptions. This situation calls for some revision if 'expectation discrepancy' is to be avoided. When perceptions are lower than expectations then the individual becomes 'vilified', when higher he becomes 'sanctified' or reverenced, and various super-human characteristics may be accredited to him. The medieval 'sanctification' or reverencing of dying persons, discussed in Section I also set the dying person apart from others, and was a form of anormalisation, although this practice was linked to the religious norms of the day.

The Illness Experience.

In differentiating between the concepts of disease and illness Field (1976) makes the important point that whilst disease labels the form of ill health suffered, providing a diagnosis, the illness concept transcends the biological and physical consequences in including those that are social. Illness has a global impact on the life of the individual and research indicates that there are several aspects of illness experience that may impinge upon the self-esteem of the sick person, each of which will be discussed in turn. These are:
1. The experience of illness that is potentially stigmatised.
2. The experience of illness and self-blame.
3. The experience of illness and loss.
4. The experience of illness and health care.

1. The Experience of Illness that is Potentially Stigmatised

To be confronted with a diagnosis such as cancer is not only to be brought face to face with issues of fear and mortality but to the unpleasant application to the self of social feelings about such a type of chronic and possibly fatal disease; for as a member of society the patient shares the feelings of others. Goldie (1985) states:

'There is an unconscious prejudice against the sick, particularly those who do not get better. They horrify us because we cannot stand the idea that we too can become dependent and incurable' (P. 33).

This is to possess a very 'undesired differentness' and to face the realisation that there is an enlarged, and possibly enlarging, incongruence between the concept of self and the 'whole health' template.

Fabrega and Manning (1972) identify four different dimensions in illness, which determine whether it is likely to be stigmatising or not - the duration of disease episode, the likely prognosis, the degree of discomfort experienced, and the potential for self-degradation. All these are stigmatising or socially unacceptable in that they represent very undesirable differences and are embarrassing to talk about in the presence of the sufferer. In the public estimate at least, all of these
dimensions feature negatively in cancer, which has been stated to be one of the most stigmatizing of illnesses (Thauberger 1974), although when this was written AIDS had not come into public consciousness.

Jory Graham (1983) writes of cancer, the disease she suffered:

'We would rather have cardio-vascular or lung disease ... agonising as these are, and many are far worse than cancer. They seem somehow cleaner more acceptable. Cancer is seen as unutterably foul'. (P. 3)

Ryan (1979) stated from his experience as a patient:

'The word cancer triggers about the same kind of paralyzing fear as leprosy or plague'. (P. 97)

If cancer is thought by some to be stigmatising then some of its effects may be doubly so, for they are feared as likely to render the sufferer even less socially acceptable. These are effects such as uncontrolled incontinence, fits, odorous fungating wounds, and various types of mutilation of the body. Mental illness is also associated with stigma (Fabrega and Manning, 1972), it would therefore seem likely that a patient with a diagnosis of brain tumour would be vulnerable to feeling 'discredited' (Goffman, 1963). For to have cancer is one thing, to have a form of cancer which immediately brings into doubt, in the mind of the sufferer and of others, the individual's competence and continued rationality is another.
However to have an experience of cancer is not to be so very 'different' for one in three persons are expected to contract it, and many people therefore have some friend or member of their family who has it. Despite the potential for stigma, research indicates that although there may be much in the cancer experience to reduce self-esteem, this is not the outcome for many patients. They may not meet or perceive some of the esteem reducing factors in potentially demeaning situations, or if they do, they may handle them in other ways than taking to themselves the lowered values or expectations of 'the other'. Plumb (1977) compared psychological function between 97 patients with advanced cancer, 66 next of kin and 99 healthy individuals. He concluded that the self-esteem of the typical advanced cancer patient and of his next of kin was relatively intact, and that the cancer patient with marked guilt, loss of self-regard and feelings of worthlessness is displaying symptoms that should be evaluated by a psychiatrist.

These and other findings (e.g Morris, 1985) indicate that it is erroneous to assume that cancer patients automatically have a low sense of self-esteem. Some may feel affirmed, and supported through good health care experiences. The response of family and friends to the situation, may be such that the individual realises as never before, how much he or she is loved and valued. Self-esteem may rise with the realisation of being able to cope, grow through, and face an experience that most people dread. The individual may feel a better person as a result (Staps 1983). By definition self-esteem is the application of worth by the self to the self; the individual does not have to accept the negative connotations of disease and may find other templates with which to make comparison.
2. The experience of illness and self-blame. It is an almost universal behaviour in the Western world to seek for the reasons for a happening, particularly if it is traumatic (Goffman, 1974). The search turns inevitably in the direction of what could have been done to merit such a disease, and its result may be lowered esteem of the self by the self and others (Blackwell, 1978). It is as if something bad must have been done for something so bad to have happened.

Ryan (1979) asked this question:

'The diagnosis is causing me, not just anguish, but anger as well. Why has cancer invaded my body?' (P. 21)

Merril (1983, x) notes that some diseases may be associated with social values of worth but not cancer. There is the vague implication of guilt.

'There is a stigma to this illness. Some diseases imply good things about you - "You work too hard so you have an ulcer. You are too competitive, you’ll have a coronary". But cancer victimizes people, and few cancer patients can write books of triumph'.

Jory Graham (1983) also explored this question and came to believe that there were four possible answers, the first two were related to personal guilt or inadequacy - God has selected this illness for me as a punishment, I have brought this on myself for I am a failure as a human being, society is doing this to me, or the universe is absurd - the
tragedies that befall us are a matter of luck - luck is random - this just happened to catch me.

Whether feelings about past life relate to actual or imagined inadequacy, modern discovery of the aetiology of many diseases, and the increasing emphasis on individuals taking personal responsibility for healthy lifestyles, is likely to produce an enlarging base for illness related guilt, as for example, in what is known of the relationship of smoking to lung cancer, and excessive drinking to liver and throat cancer. Peck (1971) interviewed 50 cancer patients between the ages of 14 and 80 years and identified types of guilt associated with the disease, they included previous life-style, other behaviours and the apparent mishandling of the illness in its earlier stages.

There is sometimes another source of self-blame and low self-esteem in the illness experience; this is clinical depression: and unacceptable identity can be the outcome for it is recognised as a symptom of the condition. On top of this, low self-value can be socially conditioned in that people are often erroneously blamed for the depression that they suffer. As was discussed in Section VI cancer patients, in various stages of the disease, are subjected to psychological stress, feelings of depression, self-blame, worthlessness, and loneliness (Krant, 1974; Polivy, 1977); for apart from the overtly demeaning aspects, many have lower control than 'normals' over thoughts and feelings, as an outcome of the unpleasant sensation that they are sitting on a powder keg, waiting for something to happen (Schmale, 1983).
3. The experience of illness and loss. Losses encountered as part of a slow dying process are often multiple. It is not only the loss per se of abilities, body image, and much else of value in society, but it the loss of the underlying meanings. Krant (1974) states:

'Dying is the inexorable and visible eradication of culturally stated personal meanings and concepts. We define our self-image, our sense of personality in relation to the way we see ourselves fulfilling the imperatives of our cultural values. The suffering that emerges in illness is not just physical pain, but is the loss of a good self-image that depended upon being synchronous, or in touch with, those cultural values'.

(P. 34)

Maslow (1970) expressed these values in his subsidiary sets of esteem needs; all are subject to affront in severe illness. The first set centred around strength, mastery and confidence. - by the time most, but not all, patients have reached the terminal phase of cancer, there will have been a considerable loss of strength. As discussed previously in Section IV, a variety of symptoms are likely to have been experienced, which erode the strength and ability that is needed to engage in even the basic tasks of daily living.

The outcome is not only physical but social, for the patient must depend on the will, judgement, and abilities of others to make up the deficit. Strength has not only been lost but also mastery and independence. The individual has become relatively powerless and lost the freedom to
respond, when and whenever is wished to his or her own needs and that of others. As Benoliel (1977) states, dying is a social passage for what happens to anyone dying is affected by the actions and choices of others.

Maslow's second set of esteem needs were related to the desire for reputation, status, and prestige'. In that reputation and prestige are related to the respect accorded to an occupational role, people coming to the end of their lives, including the retired, will have lost some of that respect. Many of the responses to ageing are seen in terms of this perceived loss (e.g. Shanas and Binstock, 1976). The dying, of all ages, experience other losses associated with the qualities valued by society. Among these are different forms of usefulness and means of achievement. Peter Gladders, a Medical Practitioner expressed a loss, which was not only strictly occupational but one of self-fulfilment:

'I have been a giver for twenty odd years and there is a lot more I could give...to have this taken away leaves an incredible gap'.

(Video communication)

This was the situation of one who had already achieved and had, if average longevity was considered, expectations of some years of further achievement. The intense urge to achieve, and to be remembered as achieving may be heightened by the knowledge that there is little time left. For the young, who have had little opportunity to gain reputation and prestige the desire may be intense, as it was with the twenty year old, Clive Jermain. (1986). For him, the situation strongly contrasts with expectations of life for his age group:
'I am driven by a sense of ambition, wanting to leave something behind'.

As a socially valued attribute a beautiful body is also related to prestige. Cancer forms a major threat to appearance and therefore potentially to 'body image' which has been defined as 'that internal picture of the body which has been directly proven to directly effect self-image' (Silverman and Cohen, 1979). Any change in body structure or function is therefore experienced as a threat to identity (Norris, 1978). The social value given to 'the body beautiful' may be judged not only by the usefulness of its parts, but by the enormous amount of time, effort, and money expended each year on beauty products and on ways to keep the body slim and shapely.

For a relative few there is pronounced disfigurement caused by cancer or its treatment, for more there is a form of emaciation, especially in the later stages. which is akin to some of the loss of appearance experienced in old age, and which elicited in some student nurses a repugnance to touch (Norris, 1978). Gori, (1981) paints a picture of cancer patients, that will be recognised by all working in this field:

'The first lasting impression in a cancer ward is one of pitiful emaciation. Gaunt faces, bone thin limbs, wrinkled parchments of skin.' (P. 5)
Conversely, cancer treatment may produce severe obesity, eliciting a similar repugnance in the sufferer, and those with whom he comes in contact. Ryan (1979) experienced a sense of disgust at his Cushinoid state, and describes the effects that it had on his daughter, when she returned from a holiday:

'To be an eyesore is disgusting. I had not realised I was so vain. It makes me sick at heart to look at myself'. (P. 374)

'She was not prepared for the sight of a strange fat man, trying so hard to show her the father underneath'. (P. 379).

However, low self-esteem is not inevitable when there has been loss of body image. Worden (1977) took a sample of 40 patients, newly diagnosed as having breast cancer. They might have been expected to have reason for low self-esteem since they had undergone mastectomy. These patients were compared with 50 women with other types of cancer. Only 20% of breast patients and 18% of others reported the syndrome of depression, lowered self-esteem, increased health concerns and loss of energy. Few women ascribed psycho-social problems to losing their breast. Since esteem or acceptable identity is lost or gained in a social context whether it is lowered or not, in these situations, will at least partly depend upon whether others are able to relate normally to the individual concerned, in ignoring the manifestations of disease (Parkes, 1984).
4. The experience of illness and health care. The state of being a recipient of care is one of dependency upon others. For the dying, as well as for the seriously, or chronically ill, it is a state in which the most private aspects of personal life become the province of others. There is vulnerability to shame, and low self-esteem in insensitive exposure, and in depersonalising interaction. Lynd (1962) emphasises the relative and subjective nature of the embarrassed sense of shame and its essential link with exposure:

'Experiences of shame ... are experiences of exposure, exposure of peculiarly sensitive, intimate, vulnerable aspects of the self. The exposure may be to others, but whether others, are or are not involved, it is always ... exposure to one's own eyes'. (P. 27)

This exposure, physical and psychological, is more likely when illness has limited the ability of the individual to cope, and when several patients have to share a small living space - here there is little hiding place. Ryan, (1979) poignantly expresses a dilemma:

'I do not exactly trust my ability to maintain objectivity publicly unless I can release the body quakes and shocks in private. And how can you make people who haven't got cancer understand what's happened to you without having to endure their pity as well. Self pity is bad enough'. (P. 20)
Here then is much potential for embarrassment, for humans experience an over-riding concern to project, at least in public, a favourable confirmable image (Lofland, 1975).

It is also possible in the care situation to feel treated 'like a number', to experience the frustration of not being fully consulted, to have personal abilities misjudged, to have to wait helplessly for someone who does not arrive in time to attend to elimination needs. There is a considerable degree of evidence that various self-reducing experiences occur as a process of becoming institutionalised; and particularly in busy understaffed ward situations. Sometimes these are of a very disturbing nature (Kelly, 1988; Fry, 1988). For the dying, such poor situations, may have an additional import, being seen to be deeply symbolic of the whole experience of loss; an anticipation of demise (Qvarnstrom, 1978).

Social institutions often make much use of symbols to convey messages of worth and value. The higher an individual rises in a business enterprise the more likely he is to be surrounded by high quality objects. Expensive fittings, thick carpets, attention to aesthetic details are symbols that reflect the importance and worth of an institution, its staff or its clients. Such symbols are the expected accompaniments of the powerful as well as the rich and famous; they are indicators that the individuals to whom they are applied are worth the trouble and expense incurred, and as such they boost self-esteem. They are used in private health care facilities. Conversely, association with the strictly utilitarian may diminish the esteem of a patient already sensitised by a stigmatised
illness. A lower and unacceptable template is being offered. David Watson, (1984) describes his feelings on visiting a hospital as an outpatient. He had been recently diagnosed as having cancer:

'The corridor in which we sat was totally bare without even colourful posters to relieve the institutional painted walls- the combination of factors surrounding my visit was totally depressing. My spirits sank to a record low and it was several days before I began to recover. I felt little more than a slab of meat placed before sophisticated scientific instruments for the benefits of measuring disease. I was no longer a human being'. (P. 83)

Another potential source of low esteem in the care situation is feeling labelled. To feel viewed, mainly, as a theoretical category, as part of a stereotype, has the potential to deeply demean and alienate patients. The less there is emphasis on uniqueness and individuality, the more the patient becomes an object, something less than human. In recent years, as nurses and others, have sought to focus on the 'whole patient', there has been a tendency to denigrate traditional 'diagnosis only' approaches to the patient as a form of reductionism. The inappropriate use of psycho-social models can be equally as reducing. In the eagerness to grasp at knowledge not available to the personal experience of the healthy, dying trajectories, stages of dying, (e.g Kubler-Ross, 1970) have been misused, and applied in ways that researchers did not intend (Ainsworth-Smith, and Speck, 1982). The patient has been fitted to the model rather than the model to the patient.
To be understood largely in terms of a stage or category, to feel intense feelings may be diminished in this way, is demeaning, and is also frightening, for it bodes ill for the time a patient may become helpless, for if he is not treated as unique now, he might not be then. As a patient, Jory Graham (1983) was aware of this possibility and expresses her abhorrence and fear of a trend she observed in the United States:

‘My one reservation about the hospice movement is that, in trying to achieve uniform standards ... the planners may unwittingly try to programme dying. Our dying cannot be converted into pseudo-scientific stages labelled "bargaining" or "denial". It is not comparable to a flu that follows a well defined course. I am filled with misgiving when I meet people who have read one book, attended one lecture or taken one course on "death and dying" and believe they are experts. I see how much they muck up the lives of individuals who are indeed dying ... No one needs such presumptive and condescending care’. (P. 127-128)

Another danger to the self-esteem of the patient may arise when professionals firmly centre their goals around one ideology that is inappropriate for an individual. Particularly is this dangerous when a vulnerable patient has respect for the professional concerned. In the field of terminal care vulnerability may exist over certain definitions as to what is a ‘dignified’ death. For whilst there is consensus among professionals that patients should be helped towards a ‘dignified death’, the concept ‘dignified’ may be defined in different ways. Some see a ‘dignified death’ as basically one without abject terror (Feifel, 1977;
Toff, 1979), although, for them and for others, a variety of positive factors come into an 'appropriate death' (Weisman, 1972). When this is the definition, various styles of dying can be recognised as valid to goals, including the 'fighting style' (McCoy, 1974); for fight has positive qualities. Moreover, if it, or any other style, is a retention of the identity and integrity of the patient, then it corresponds to a definition of dignity.

To others, dying with dignity has a narrower interpretation, as being synonymous with acceptance by the patient of the dying state; for this is viewed as signifying successful achievement in the last developmental stage of life. Poss (1981) expresses this point of view as she writes for fellow professionals and students:

"The mandate for caring stands to help the dying person to reach a contemplative integration of his life. In so doing the patient will have accomplished growth, integration and fulfilment ... A great deal of energy and effort are required to resolve the crisis involved in dying. Hence the patient cannot master the terminal crisis, that is he cannot die with dignity, until his dying work has been completed. Dignified dying and 'acceptance of death' will be used synonymously to indicate the optimal outcome of dying work completed'. (P. 5)

As an aim to help the dying to disengage from life, this goal is more understandable than when acceptance alone is equated with dignity. Much will depend upon how an experienced professional handles a situation of
unlikely 'optimal outcome'. If the patient perceives an inability to meet the expectations of those who are valued then a sense of failure and low self-esteem may result, described by Popa and Hanganu (1979) as 'iatrogenic despair'.

As research indicates many patients reach an advanced state of cancer without gaining low esteem in the experience, and many factors are involved. In that of care there is potential to lose, retain or gain sense of acceptable identity.

RESEARCH DATA - ACCEPTABLE AND UNACCEPTABLE IDENTITY

Acceptable identity, in terms of creditability to the self and others emerged quite spontaneously in the response as an important quality of life factor to 31 (60%) of hospice 'random' sample patients, and to 15 (68%) of hospital patients. There were two main ways in which acceptable identity was expressed; it was expressed in terms of default, and related to losses of ability, to a sense of guilt, to shame at the invasion of personal privacy and having to accept standards of living less than the norm; such statements were accompanied by indications of dissatisfaction. Acceptable identity was expressed positively through an emphasis on personal attributes - role and status, and accompanied by a sense of pride and satisfaction. A greater proportion of women than men, in both samples, made identity related statements - in the hospice 'random' sample 67% of women compared with 50% of men, and in the hospital 80% of women compared with 57% of men.
A sense of identity that was in some way spoiled came first from various types of actual or potential losses of ability, of privacy, of standards of living, and secondly from different types of guilt. Response with negative connotations for an acceptable sense of identity was expressed by 19 (37%) of the hospice 'random' sample and 8 (27%) of the hospital sample, and was accompanied by expressions of sadness and dissatisfaction; the former included statements about past hospital experience.

Lost Ability

There was often a very pronounced sense of loss as people spoke of the effects of the disease on physical ability; they were engaged in a struggle to retain what they could. The concept featured here was one of reduction often associated with the phrase 'I was'. Men particularly mourned the loss of physical prowess. For example:

Mr F (Hospice) aged 44, 'I was knocking down trees two years ago. Now I can't do anything - even close my fist (demonstrated). He spent some time searching for something in a book and when offered help said: 'Oh no, you must do what you can for yourself - every bit. You, must use your talents all your life - remember the parable of the talents - if you don't use them they are taken away from you'.
Mr R (Hospice) Aged 45, 'For me, five weeks ago I was riding my push-bike. I have put it up for sale - shall never ride it again. I was a keep fit person'.

Mr A (Hospice) Aged 70, had been particularly proud of his connection with boxing:

'I gave boxing instruction for charity and got a big kick out of it - was an amateur and professional boxer four years ago. I coached an amateur schoolboy champion (showed photo) - I trained some of the boys' fathers too - up to four months ago I was still training, it's a big blow when something happens like this'.

It was very important to him the way staff spoke to him and the respect that they showed, and also the degree to which he was able to retain independence:

'I am sure I can do most things they musn't assume that we are all hopeless'.

A characteristic of those who spoke most of loss was that they were younger than the majority of the sample, and had recently been working; the elderly may expect to have lost vitality and work-role but not the middle-aged. Two had an 'athletic image' which contrasted strongly with their present condition. For two, there was also a time-element factor - their illness had progressed so rapidly that there had been little time to come to terms with it:
Two women particularly mourned the loss of a role in helping the handicapped, one is noted in chapter 8 - now it was they who were the patients. Mrs J (Hospice) aged 55 said:

'It's hard to be disabled, particularly since I used to look after the disabled. Now it's the other side of the coin'. (Repeated later in the interview) Her reaction was one of depression.

A factor that added another dimension of reduction for two of these patients (and for two others) was having a brain tumour, for this was associated with a stigmatised incapability of another order; all four patients with brain cancer linked their disease with some concept related to low esteem or stigma. Their comments underlined some of the additional suffering associated with illness that is viewed as 'discrediting' in this way. For example:

Mrs D (Hospice) 'I am hanging on to my identity for all I am worth'. (tears) ... It seems to me that you are doing something very useful, I am a prolix lady and will say it while I can'.

Mr R (Hospice) 'It is a bit of a blow - I went to X Ray - had a scan. They operated and it didn't work, so they said - that's it. So I was told I had a malignant tumour. See my body is all perfect but it is my brain that is all knackered'. (First Response) In the light of this it was particularly important to Mr R to be treated as if he were rational and responsible. Given that situation what helps? 'Not a lot but this place has helped me tremendously. I said to the
doctor, "Tell me straight", and he did. It’s important that they should communicate. Yes, I am not an idiot. I know the score’.

Having to Accept Lower Standards

Loss of control of the body can have secondary effects that add to the feeling of being demeaned or downgraded in having to accept standards of living that are lower than usual - the effects are social as well as physical:

Mrs D (Hospice) ‘I spilt water on my nightie and had to wear one of theirs. I didn’t want to. (tears) You might say that I was jolly lucky to have another nightie from another source but that does not strike me like that’.

Embarrassment and Helplessness

Embarrassment and powerlessness were other esteem reducing concepts that appeared particularly in the response of women. Helplessness involves the intrusion of others into what had previously been a personal or private affair:

Mrs P (Hospice) ‘Not being able to cope or feed yourself, that’s what gets me, them having to feed me’. (First response)

Mrs N (Hospice) ‘I feel extremely embarrassed about my bowels’.

Mrs D (Hospice) ‘Yesterday I had suppositories and also bowel treatment - it hurt, was shocking, shaming and necessary but now
thank goodness it is all different, which proves what my mother used to say, "Nothing goes on for ever".

Mrs D often spoke in terms of symbols - her sense of relative powerlessness came over as she quoted a rhyme she felt was relevant to her situation of being prescribed blue pills:

'The tailor thought his mouse was ill,
Hey diddly um tum tweedle,
So he gave him half of a blue pill,
Hey diddly um tum tweedle'.

To have a loss of physical ability with forced dependence upon others is loss enough, but with handicap goes the danger that the whole person will be assessed in the light of that handicap. There is potential for secondary loss of esteem. Mr C (Hospice) was invited to complete the Visual Analogue Scale, but suffered a degree of paralysis of his arm. He was very quick to point this out lest a further assumption should be automatically made:

'I can never do measures because of this arm. I was a good scholar'.

**Sense of Guilt**

A different sense of feeling less creditable, at least to the self, came from the feeling of guilt or self blame, which surfaced in relation to
the illness. This was expressed by 3 (6%) of the hospice 'random' sample and others in the convenience sample there, and 2 (9%) of the hospital sample. There were three types of guilt expressed, the first two were illness related. These were:

1. Guilt in terms of perceived responsibility for the illness or for its advance.
2. Guilt at perceptions of not coming up to staff expectations.
3. Guilt for past behaviour unrelated to illness

**Perceived responsibility for the illness** Three patients felt at least some responsibility for their disease, or the state it had reached - Mr I (Hospice) felt that he might not have contracted either his cancer of the liver or his emphysema if he had not indulged so much in drinking and smoking:

'People abuse themselves. I did all that smoking and drinking. It could have made a difference of a year or so. After all you are taking in the kind of stuff that is used as a weed killer. It's a pity you can't think about it when you are young - smoking and drinking and the way you live - my parents were horrified when I smoked'.

Two patients felt that the disease might not have advanced if they had taken appropriate action at the beginning:

Miss ID (Hospice) 'When I first became ill I should have given in my notice and taken a less materialistic life-style, but there was the
mortgage. I could have managed but wasn't willing to give it up; now I can see that material possessions, a nice house and garden are not essential. I regret now that I didn't give up'.

Miss LD (Hospice) had suffered from agoraphobia and delayed going to her doctor until it was too late:

'I suffer from self-destruction. Now I have really brought this on myself by not going to the doctor's - I did not go until I realised something was seriously wrong - if you have never had someone wishing they would be ill you now have it. I have always been suspicious of everything. Now I've done it but I don't want to die'.

Guilt at perceptions of not coming up to staff expectations Perhaps the saddest sense of guilt came from those, who because of their condition, felt they could not come up to what they perceived to be the expectations of those who were helping them. The first Mrs D was considered at this point to be clinically depressed - a condition in which there are often feelings of guilt.

'The idea downstairs in therapy is that you are expected to stay from 1.30 - 3.30 at least, and I have not managed to do it because a restlessness boils up within me. Yet what I am doing is exactly what I chose to do myself, practising my left hand. I have marvellous painting brushes given me by my friends. I wanted very much to stay. These good girls here expect me back at 3.30. They are busy until then. I am always being the guilty one. (tears) 'Guilt is my
temperament and it is worse than ever now, so Dr X gives me some blue pills ... If you come again I will tell you what the blue pills have done for me’.

Mrs PF (Hospital) ‘I was naughty last night. I just could not get up. They said I had to help myself. I got all het up, my leg wouldn’t work. This morning I apologised and they said, "It is part of the job".

Mrs A (Hospice) was said by staff to be deteriorating. She said, ‘Today I have been very naughty, my kidneys have to be flushed and I am not drinking as I should ... I have been very sleepy today ... I am not at my best today’.

Guilt for past behaviour Two patients expressed a sense of guilt about past behaviour as they reviewed their lives (research identification withheld), they did not relate this to their illness:

(Hospice) ‘For many years I have lived contrary to the laws of society’.

(Hospital) ‘I am a wicked man’ - my father was no good - my family are no good - my son is in prison’.

There was much in the illness situation with potential for demoralising guilt, whether this was justified or not - ‘having’ the illness, not
being a 'good' patient, and the guilt arising from life-review stimulated by the perception of being seriously ill.

ACCEPTABLE IDENTITY AND ENHANCED QUALITY OF LIFE

Thirteen (25%) of hospice 'random' sample patients and 8 (36%) of hospital patients spontaneously shared aspects of acceptable identity at interview. It seemed to give them satisfaction and a sense of pride to do so. Acceptable identity was shared within four meaning contexts. These were:

1. Having achieved high ranking occupational role.
2. Having socially valued expertise.
3. Having a socially valued role.
4. Having personal qualities in coping with the illness.

In the interest of maintaining complete confidentiality, references to occupation, will not be accompanied by the usual research identification in the examples.

Achieved high rank Here role and status came to the fore, and was often introduced fairly early on in the interview within the meaning context of describing personal attitude and action - of stating I am this sort of person because I was this, and achieved this, in it:

'I was a headmistress' - for Miss X her identity as a headmistress, as a leader in teaching, was very important to her, so much so that she saw everything that she did in the light of this. She was talking about being able to vent her anger and said, 'I was talking
to S (another patient) and she said it would be better for me if I wanted to curse and blast to do it. But you know my role in life has been to be a teacher - and cursing and blasting are not what you do - the last thing. Everything else has failed if you have to do that. I never let myself go. I was so incensed a few days ago that the timbre of my voice went completely haywire and I was squealing like a fishwife. I didn't like myself because I was doing what I had vowed I would never do, and I was doing that so badly'.

'I am an old soldier, finished up with rank of Major' - for Mr Y his profession as a fighter was also firmly linked to his means of coping with his illness which was through fight. 'Life is everything - I am going to get better - have fought in the past and won'.

Having Socially Valued Expertise Information on role and status was often offered as a justification of ability to comment usefully on certain issues appertaining to the present situation. For example:

'I am a playwright and have been in the theatre most of my life, so I ask questions'.

'In my experience in the NHS'.

'The food is always punctual you are not kept hanging around. Having been in catering all my life I notice these things'.
'I had a job as a receptionist for Social Services and had to learn how to handle people'.

A greater proportion of men than women in both samples used past occupational role as a symbol of acceptable identity than women, although this was very marginal in the hospice. that is, 18% of men in the hospice 'random' sample compared with 17% of the women, and 43% of the men in the hospital compared with 7% of the women.

Having a Socially Valuable Role Others spoke of having certain valued qualities and abilities which centred around useful social, but not occupational, roles. For example:

Mr C (Hospital) 'My thing in life is to be useful'.

Mrs D 'I have sung in the church choir.'

Mrs C (Hospital) 'I used to write scripts for the Townswomen's Guild plays'.

Having Socially Respected Qualities The many references of this kind are discussed in chapter 9. Here are two examples that emphasise satisfaction in individuality, and a sense of pride in having the kind of qualities consistent with coping
Mr AD (Hospice) 'It depends upon what sort of person you are talking to; if someone asked me I would just turn round and say I am thankful - I appreciate things'.

Mrs PK (Hospital) 'I can never understand - some people are never happy'. unless they are miserable. I am trying to grow old gracefully, which is very difficult'. (laughed).

CONCLUSIONS
The importance of acceptable identity to quality of life has been first seen in the sorrow of those in whom creditable aspects of identity have been eroded by illness, and in those who have a sense of failure. There was much in the illness situation with potential for loss of esteem - loss of ability - of social role - potential loss of mental control in having a brain tumour - having to live by standards less than the norm - embarrassment at the loss of bodily privacy in helplessness - a sense of guilt related to the illness or past life.

Expectations and reference groups have played a part in the sense of lost identity - these have related to lost abilities and lost norms of living. The relevance of expectations has also been shown in the standards of behaviour and styles of coping that individuals expected of themselves, as well as to their expectations of ability to talk usefully on a subject. When expectations have not been met, by the self or others, then there has been a sense of loss of acceptable identity; when they have been met, one in which acceptable identity has been maintained.
Some gender effects appeared in the response; a greater proportion of women than men, in both main samples, made identity related comments. Men focused more on the loss of physical prowess; women on the loss of helping roles, and on the embarrassment associated with helplessness and subsequent loss of bodily privacy. A greater proportion of men than women in both samples used occupational role as a means of expressing creditable identity.

The importance of acceptable identity has also been seen in the readiness and eagerness of so many respondents to spontaneously share that which has been positive. Sharing is a means of affirming identity to the self, as well as inviting the active listening and response, that confirms the recognition of the 'other'. Occupational, social and family roles and personal qualities accord a place within human ranks, whereby the value and usefulness of the individual is judged, they had remained important to many of these respondents who had carried their sense of role identity through years of retirement and into the care situation. Acceptable identity was an important quality of life factor for these respondents.
The last chapter has explored the importance of acceptable or creditable identity to the quality of life of respondents. The response has indicated the demoralising effects of loss of ability, of having to accept lower standards of living, of dependency and embarrassment, and of illness related guilt; and the efforts to retain what was possible in the face of progressing disease. This chapter uses the rest of the response on this subject to explore how acceptable identity was gained or lost in the care situation. It suggests that maintaining acceptable identity should be a major aim in care.

MAINTAINING ACCEPTABLE IDENTITY

The data of the last chapter and of this suggests that if the goal of care is to enable the patient to attain maximum quality of life then one of the major aims must be that of maintaining acceptable identity. As has been seen acceptable identity has many aspects and many sources of loss. Acceptable identity is rich in symbolic meanings - therefore the expectations of care should be that attention needs to be paid to these many meanings. There are several ways in which acceptable identity was enhanced or diminished in the care situation.

Acceptable Identity and Maintaining Ability

In this section the key concepts were independence, mobility, normality, and symptom control. The data indicates that retention of the maximum possible degree of mobility is a key factor in keeping a desirable sense
of identity, for it staves off dependency, so often felt to be demeaning, and gives the individual more potential to live life as he or she wishes. It was a priority for patients:

Mr T (Hospice) 'To keep walking'

For Mr ED (Hospice) it was a matter of bargaining:

'Just to get better - to improve my health so that I can walk about, even if it is not running the four minute mile'.

When some ability had already been lost it was important to maximise that which was left.

Mrs D (Hospice) had lost the use of her dominant right arm. Her first response to a third interview was expressed with some excitement:

'There have been developments - I may be barmy - Dr. X has given me the task of wording the placards for the music programme on Friday - this I have done with my left hand. They say they are clear (pride in tone). She returned to this theme when asked to evaluate her quality of life at the end of the interview:
FEELINGS ABOUT QUALITY OF LIFE AT PRESENT

Delighted/ Terrible

'Because I am going downstairs to write with my left hand'.

Good symptom control was an important factor in restoring and maintaining ability. Clinical experience indicates that, despite weakness, some ability may frequently be retained and sometimes regained, through combinations of approaches, including medication and physiotherapy.

Mr J (Hospice) had become completely immobilised by pain before his admission. He said:

'The pain is going down now ... I couldn't move a leg. I appreciate it a lot'.

As discussed in the last chapter mental confusion was seen to carry a stigma; the delight of Mr N (Hospice) in his restored rationality held meanings of increased credibility and greater opportunity for control of life. At the end of the interview he preferred to comment on his quality of life rather than complete the Visual Analogue Scale, and said:

'I feel good all through - I expect you know what is the matter with me. I am quite lucid now and am going to continue'.

When there had to be some degree of dependence, appropriate mechanical aids were important to quality of life for they reduced the reliance on human assistance and the waiting for help, enlarging the scope and the
control of life. It was important to have a variety of types that would maximise the limited ability of the individual. Mr N (Hospice) could now enjoy the greater freedom of a wheelchair:

'It makes me feel happy that I can move around in a wheelchair and go for walks ... being in a chair with wheels is a bonus - after all I am not inactive - all that is wrong with me is my back'.

Mr H (Hospice) had a walking aid; he was very weak. Its design enabled him to venture further in independence because he could rest as he wished. He spoke of it with great pleasure:

'It has a seat and a place for carrying articles'.

Mr H described how this had enabled him to walk in the sunshine and enjoy the garden.

Acceptable Identity and Opportunity to Express Individuality.

Carefully maintained, restored or aided ability provided a basis for acceptable identity but was insufficient in itself if energies could not be used in activity that was meaningful to individuals, through which they could express personality. This requires flexibility on the part of the organisation, and provision for choice. When traditional group type activities are all that is offered some people may feel devalued in the eyes of self as well as others, whom they perceive as having no individual expectations of them. They have become stereotyped:
Mrs D (Hospice) 'In O.T I can have enough Bingo. They arrange it very cleverly so that nearly everyone wins a prize'.

It was in response to awareness of this type of situation that around the time that these comments were made, the hospice greatly expanded its recreational activities, but this required the building of additional premises, and also the provision of extra staff who worked both in that department and in the wards. This work also heavily relied on the support, interest and encouragement of ward staff.

Mrs GD (Hospice) 'They talk about things and persuade you to do things - don't let you vegetate'.

For Mrs A (Hospice), her sense of self-esteem was boosted because the art work that she had done in the leisure centre was admired by the ward staff and hung on the wall. She said:

'We get all the encouragement possible to help ourselves - my two pictures have been hung in the ward'.

When there was choice and freedom patients were able to express their uniqueness in different ways. Mr PE (Hospital) expressed his friendly out-going personality in a desire to bring cheer to others in organised activity. He would have liked more equipment:

'More wheelchairs in the ward so you can have a race'.
For Mr L (Hospice) it was important that he had the flexibility to use his maintained energies underlining what was normality for him - his visits to local pubs.

'I like to have a drink and go out, like any normal man'.

Mrs F (Hospice) was able to expand her view of herself as with encouragement, she tackled writing poetry. She showed me one effort and said with a sense of wonderment and delight:

'You don't really think it is good do you' - it can't be - is it?'.

Mrs F was very aware of her deterioration and had a sense of loss, but this was providing some compensation in another area of life.

The research provided another medium through which people could express their individuality and could feel valued in that their personal opinion and help was of great importance. The response of Mr C (Hospice) was typical:

'If I can help you' (repeated with eagerness).
Mr J (Hospice) whose demoralising experience will be noted at the end of this chapter was more explicit about self-expression, as regards the research and his general experience:

'I like this sort of thing because I can speak my mind ... Here people are not units - just natural human beings, just speaking their minds - all our lives are similar'.

Acceptable Identity and Personal Appearance

Compared to the extensive comment on loss of physical ability and its effect on quality of life there was surprisingly little that was overt on personal appearance. However, many patients in the hospice were observed greatly enjoying the attention given by nurses to aid their beauty regime - assistance with hair, make-up, nails. Appearance was important for Miss C (Hospice):

'They are going to do my hair next week - even X (last hospital) doesn't have a hairdresser'.

and was part of vital defence and fight for Mrs MD (Hospice):

'I am sitting here painting my nails and putting on make-up. I am not just going to lie down and die - that is all that matters - all that is on my mind at present'.
It may also be that the importance of appearance was hidden within the many appreciative comments on the general help of nurses (and here the researcher wished she had probed more). For example:

Mrs H (Hospice) 'I am glad I came - the attention is wonderful',

Some patients had lost a breast, some their hair - defects that were covered up - and others were cachectic - extremely emaciated, but only one in the sample was grossly and differently disfigured from those around. It was noticeable that the few negative comments that were made on personal appearance held an extra connotation. For example, Mr R (Hospice) was annoyed at the loss of his hair in the context that it had not been properly explained to him in the hospital that this was likely to happen as part of previous treatment:

'I have lost all my ... hair and all'. Do you mind? 'Yes, but I know it is going to come back. They do things to you and they don't tell you'. Didn't they tell you? - 'No'.

As noted in chapter 6 the loss of a breast was referred to by Miss C (Hospice) as not so bad as the present sense of weakness. The patient with a badly disfigured face referred to this in terms of the rapid advance of her cancer rather than to her loss of looks.

'The cancer in my mouth is advancing so rapidly ... I don't want to die yet'.

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Here bodily change took greater importance as a symbol of deterioration than of appearance, and consistent with the Maslow (1970) hierarchy, survival was the primary consideration.

However, although this was the situation with regard to the samples of patients one incident occurred during the time of research that indicated the effect of negative social response to extreme disfigurement. One badly disfigured patient had settled in the hospice relating with those around her, because they interacted with her as if she did not have the disfigurement. One day a child accompanied a visitor and said in a loud voice, "Oh look Mummy there is a lady with only half a face". This utterly demoralised and distressed the patient and she requested that she be removed to a single room. The loss of esteem had come through her perception of the perceptions of 'another'. This is a reminder of Parkes (1984) comment that whether esteem is lowered or not partly depends upon whether others are able to relate normally in ignoring the manifestations of the disease.

Acceptable Identity and the Environment

Aesthetic values have a double importance for some people, they express the artistic and are also symbols of social worth. As discussed in the last chapter the strictly utilitarian is often reserved for those least respected, the rich and powerful are surrounded by things that are beautiful. The key concept here was the norm - living above the strictly plain and utilitarian was important to acceptable identity for several patients. For example:
Mrs P (Hospice), 'A cup of tea out of a cup, much better than a beaker - so hospitalised'.

Mrs A (Hospice) 'The way food is served, everything is served up so daintily, small portions, lace cloth'.

Mr K (Hospice) 'Millionaires also get ill, they go to BUPA places, but what more attention can they get than they get here. When my nieces and nephews saw the place they were sorry that they belonged to BUPA'.

So often those who are sick have to accept conditions in care that are far removed from social norms of living; whilst this may be taken for granted by some it is not by others who see this as further evidence of the general downgrading of identity imposed by the illness. For example, it is not the social norm for elimination processes to be accomplished in small rooms, full of people (patients and visitors), with only a curtain as a shield. Such situations are set against such concerns as immobility, and the need for urgency. but it is a pity that there is not more provision for patients to be quickly moved, when they wish, to some more private and easily accessible space:

Mrs D (Hospice) had bowel problems. She said:

'Did I say anything about what a time it takes sitting on the commode, and how degrading it is to sit there'.
Acceptable Identity and Qualities of Interaction with Staff

There was much response on the importance to quality of life of various aspects of interaction with staff. Here the key concept was 'the way' the patient was approached - the humility and respect of staff, or negatively their disregard and disrespect. Respondents did not demand special treatment - acceptable identity here centred around the norms of courtesy, and being treated as an individual; to be courteous being defined as 'polite, considerate or respectful in manner and action' (Chambers, 1973:299).

Fundamental to esteem in any relationship, is being recognised by name. It is the first mark of individuality, the antithesis of being 'a number'. This was stated to be important by several respondents; it was recognition within the reasonable bounds of time that mattered.

Mr PD (Hospital) 'They know your name quite quickly'.

Mrs M (Hospice) 'I hadn't been here very long and someone came and asked for me by name (the chaplain). Strange someone knowing me as a person'. Mrs M seemed very surprised at this - these were not her expectations of institutional care.

Mr B (Hospice) was another who expressed surprise. He said:

'They will help you at X (past hospital) but the atmosphere was different - you usually walk in and are a number'.
The way a patient was approached was particularly important:

Mrs PA (Hospital) ‘The way the doctor approaches - shakes hands - sometimes holds your hand - especially the lady doctor’.

Mrs PN (Hospital) ‘The nurses are like ladies, the doctors like gentlemen’.

Mrs C (Hospice) ‘The doctors and nurses the way they talk to you, kind and meek. No roughness in their tone of voice’.

It was the humility of ‘experts’, their interest and the time they gave that boosted acceptable identity, for they were seen as busy and important people.

Mr PG (Hospital) had learnt that morning of his prognosis, ‘The doctor was so nice this morning. She talks to one, although she is the consultant’.

Kindness alone could be seen as patronizing:

Mr PB (Hospital) ‘Kindness - alright in terms of a child - (otherwise) - patronizing’.

Dignity demanded the possibility of being able to reciprocate in relationships, at least in terms of warmth. Mr U (Hospice) made this statement with regard to relationships with staff:
‘Dignity is love and affection for each other’.

Acceptable identity was also boosted when staff demonstrated that their work of caring was acceptable to them; to feel an unacceptable burden was demeaning. References to the importance of not feeling a burden to staff were spontaneously made by 5 (10%) of the hospice ‘random’ sample and by 5 (23%) of the hospital sample. For example:

Mrs PB (Hospital) ‘Nice when you see staff are happy - don’t take it as drudgery ... it can be very monotonous but they don’t show it ... staff going about their work as if it is a pleasure to them - it is not too assuring to you if you see them unhappy’.

Mr C (Hospice), ‘I don’t want to be no trouble to no-one’.

The way help was given was as important as what help was given, in symbolising whether the task was acceptable to the nurse. Miss D (Hospice):

‘They have been so kind. I can’t thank them enough - in fact I didn’t want to live’. What are the kindnesses? ‘The bedpan, the way they wash you - bless them - it’s wonderful to me. I have always done it for other people - never thought I would come to this ... the way they are kind does make you feel better, it’s very important. You say you are a trouble. They say you are not’ ... A thing happened to me - I did something in the bed - there was never a cross word’.
Some factors were expressed negatively, tone of voice was important and could be devastating even if the words were not:

Mrs D (Hospice) 'S (with facial cancer) - sometimes her mouth dribbles - a member of the staff was so cutting about it - "wipe your mouth - it's dripping" - it was the tone of her voice, not the words'.

And, not having the full attention of nurses whilst receiving care was symbolic of being valued as an object:

Mrs D (Hospice) 'Not liking nurses continuing their conversation when I am present, because it seems as if they are treating me like a piece of furniture, and not concentrating upon me at all'.

Having a kind of imposed saintliness on the self was equated with unacceptable identity of a different kind for Miss LD (Hospice) for she was aware that this was inconsistent with reality:

'I don't like the fact that people are goody-goodies when they become terminally ill. They are still bitchy. I have a good relationship with people and can still speak my mind. It is important - you have got to keep hold of reality - things could become unnatural with a halo round your head'
There was evidence that certain situations increased the risk of patients perceiving themselves as devalued or less than human. Lack of time was equated with failure to approach the patient as an individual:

Mr A (Hospice) 'The staff the way they talk to you - in general hospitals they have not the time - they speak to you in such a rigid way

References to the busyness of staff have been made in chapter 7.

Acceptable Identity and Choice and Control in Dependency

When the situation was one of dependency then the help of others was often much appreciated for it aided bodily comfort and the dignity of cleanliness, freshness and acceptable appearance, but alongside the many appreciative comments on the help of nurses there was an emphasis on control. The key concepts in this section are help, dignity, choice and control. Control through the nurse rather than over the nurse was implied; such control offset feelings of powerlessness, and is related to physical comfort in chapter 7 and styles of coping in chapter 9. For example:

Mr PG (Hospital) 'The nurses and the way they treat you and look after you, what you want they do.

Many comments underlined the importance of Henderson’s (1979) use of the phrase ‘assisting the patient’ in her definition of nursing; for assisting acknowledges the right of some other to control. For example,
assisting the patient to dress is different from dressing the patient although the nurse's actions and eventual outcome might be the same, for in the former the patient necessarily has control and the opportunity to express choice and individuality in the latter he or she does not. Mr R (Hospice) was very aware of this difference. At the time he might have been somewhat confused but not so much that he was unable to feel angry and demeaned:

'I have had five weeks in the other place, not good compared with here. I was saying, "I want this shirt and want that. They took no notice of you because you were a bit sick. I know what I am doing, my brain is ice cool. Women like that won't get it into their skulls, I am not a two year old baby. They are thinking for you, they forget you have a brain of your own (swore). When the time comes for the nurses to go home they go home but I have to wear my gear all the time, at least here you can get your own way - tell people how you feel. To me this is quite important. I don't mean to be rude to women as nurses - just because I am a little bit ill doesn't give them the right. I have brought up three kids and have a grand-daughter'.

Some statements underlined the sensitivity that is required in helping dependent patients, for loss of ability may be felt acutely and dependency can be perceived by some to be very demeaning:

Mrs D (Hospice) 'These good girls do not know that there is any difference from using my efforts to theirs'.
And, to under-estimate the ability that remains can be hard to bear especially when there is the fear that it is eventually going to be lost:

Mr A (Hospice) 'This morning I felt I had just a little bit of over-attentiveness - doing too much for me. I am sure I can do most things. They mustn't assume that we are all hopeless. Everybody likes a certain amount of independence. As long as they see you can do it they should let you if you can'.

Mr PB (Hospital) also found dependency very embarrassing, and as he was in his 70s perceived underestimate of what he could do as labelling him as being 'geriatric'. His dignity was further affronted in that when he complained he was given no explanation that was reasonable to him, and was then left with his feelings. He was hurt and angry at interview:

'There was an incident this morning. I wanted a bath and the nurse said I had to wait until she was available - why?. She said I can't get in and out on my own, it is not allowed. I only have a gammy leg and am not a geriatric. I could do so last time I was here. It's your dignity. You are reduced enough without being reduced further. I know nurses get used to men but I don't want one to help me in the bath. She forgot to come back later - you get a few like that'.

This incident also has an implication for the support and preparation needed by nurses - for often a young nurse may be asked to do something and may suddenly be confronted by a situation such as this and not be able to handle it diplomatically, for she may have neither the skill nor
the authority to be flexible. It is not known whether the nurse really
did forget to come back, she may have 'run away' from a situation she
found hard to face.

One danger of offering more help than is necessary is that it leads to
increased dependence.

Miss ID (Hospice) 'I enjoy the daytime here - very pleasant and
peaceful, but one could become so passive. The nurses are so nice
and kind, at one's beck and call all the time. I could become so
easily institutionalised - asking for things and they are so easily
produced'.

It is often assumed that in the interests of self-esteem all patients
should be encouraged to undertake as much of their personal care as
possible, and many of the references here would support this. However, as
will be noted in the next section, Miss ID and three other patients
suggested that there might be a priority in activities, and that help
with some of the basic tasks enabled them to use their limited energies
in activities that were more meaningful. To be reduced to dressing and
washing and have no energy for anything else can be equally demeaning in
that it denies opportunity to achieve in other morale boosting and self
expressing ways. This seems particularly important when energies are
diminishing in terminal illness and when the patient may wish to do
something special or undertake some 'unfinished business'.
Many symbols of identity have been discussed. It is probable that several need to come together to provide a strong sense of acceptable or unacceptable identity. Here organisational, environmental and interaction factors of the past had combined to produce a clear negative message for Mr I (Hospice):

‘Other hospital - was put in a geriatric ward - you might as well have been a bush animal - chucked me in a dirty bed up besides the toilets. They had a big sister and a wee skinny nurse who couldn’t lift anything. When I was there a man couldn’t get up to the toilet. He shouted and no-one came - he just lay there. I had a shout. Eventually a nurse came and said he was too heavy for her to lift. What is she a nurse for then? The things she said to me the next morning. She gave me rough treatment. I wanted a two pin plug to put in my shaver. She said, "I haven’t time", She thought I was an American and said, "Why don’t you go back to where you belong. If I had a gun I would like to shoot the lot of you". Those poor men who had fought for their country. I told my doctor who said I should take it up. I said I would never go in there again. That is why I am in here, no comparison. In there I would have been just a bag of waste’.

There have been several factors with potential for less than acceptable identity - lost abilities and dependence on others, a sense of guilt or depression; particularly there has been the feared loss of mental ability and some bad experiences in past care. However not all those who were heavily dependent felt demeaned, their feelings were influenced by the
way staff approached the situation. The comments in the hospice and hospital indicate how vital this is.

As will be further discussed in chapter 18 two-thirds of hospice 'random' sample patients made some comment comparing the hospice with past hospital experience. Twelve (23%) of this hospice sample, compared the hospice favourably to their past hospital as regards factors that would be likely to contribute to the patients self-esteem in being treated as an individual with some choice and control, feeling wanted, and valued in the warmth of a relationship. (Table 15.1):

Table 15.1 Self-esteem issues in which 12 hospice 'random' sample patients spontaneously compared past hospitals with the hospice.

<table>
<thead>
<tr>
<th>Other Hospital</th>
<th>No. of comments*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not so much choice and control for patient</td>
<td>3</td>
</tr>
<tr>
<td>Staff not having time for patients</td>
<td>3</td>
</tr>
<tr>
<td>Staff not being so friendly/kindly towards patients</td>
<td>12</td>
</tr>
</tbody>
</table>

* Some patients made more than one comment.

The issues here are relevant to the personal qualities of staff, their understanding of the needs of patients, as well as for staffing levels, pressure of work and the need for staff support. The experiences cited had an on-going relevance to the patients concerned, for the memories went with them, and appeared to make them particularly sensitive to issues of self-esteem.

CONCLUSIONS

The overall conclusion from the evidence of these two chapters is that
acceptable identity was a major quality of life factor for these respondents, and that there was potential for its frailty in the illness situation. However few indicated that they felt demeaned and for many their sense of self-esteem had been boosted in the care that they received.

Organisation of Care, Expertise in Care, Interaction in Care?
The organisation of care, the expertise in care and the interactions in care have all had an influence on acceptable and unacceptable identity - on enhanced or diminished quality of life. Organisational factors have included an environment that when aesthetically pleasing and attractive reflects the high value of the patient, systems of care and staffing levels that enable the patient to feel treated as an individual, and facilities that provide opportunity to express individuality and to achieve.

The expertise of a team of professionals has contributed in care of the body and in symptom control. This has restored the abilities and appearance of some and maintained that of others; with a potential not only for physical rehabilitation but for that of identity too. Empathy coupled with skilled assessment has eased unacceptable identity with listening and counselling. Choice, when the patient has been well enough to make it, has been important to esteem in encounters with professionals.

The effects of the interactions of members of staff with patients - different disciplines, the experienced and not so experienced, indicates
that all contribute to the patient's sense of identity: and that what is
done and the way it is done, and what is said, and the way it is said is
vital to a vulnerable sense of identity. Manner of approach has been
important, and staff listening to patients' descriptions of their own
occupational, social and family roles helps to affirm identity.

Reference groups in terms of past hospital experience has formed part of
the background of the response against which the present has been
evaluated. Expectations have formed much of the context within which this
response has been presented for when conditions of care and interactions
with staff have fallen below the perceived norms then the patient has
been demoralised; when they have been consistent with expectations or
have exceeded them then the sense of self-worth has been enhanced.

However, acceptable identity for these patients has not meant receiving
any great luxury or unusual recognition but being recognised as their
individual selves and given the opportunity to live as nearly as possible
as themselves - being able to give in terms of opinion and warmth as well
as to receive, and being approached with all the norms and respects due
to social human beings. Some past experiences of patients indicate that
esteem boosting factors may be in short supply in some hospital wards,
for there these patients were made to feel less than individuals, and a
burden to staff. There is every reason that maintenance of acceptable
identity should be a major goal in care, with its symbolic implications
understood, if being physically reduced is not to be turned into feeling
socially demeaned.
SECTION VIII

QUALITY OF LIFE AND HAVING PURPOSE FOR LIVING
This section focuses on the importance to the quality of life of respondents of having, or finding, a sense of purpose in life, that is, an overarching purpose or philosophy for living and dying, or purpose in the daily acts of living. Purpose, in one or other, or both of these forms was spontaneously expressed as important by fourteen (27%) of the hospice 'random' sample and six (27%) of the hospital sample.

Purpose is defined as 'an idea or aim kept before the mind as the end of effort' (Chambers, 1970:1094), it therefore something to strive towards, and provides a reason for effort, denoting some stability of attitude towards that effort. Purpose is linked to meaning in that to have meaning is defined as to have 'purpose' (Chambers, 1970:812). This chapter explores these aspects of purpose and relates them to quality of life. Chapter 17 relates them to the provision of care.

BACKGROUND - PURPOSE FOR LIFE AND PURPOSES IN LIVING

For the purposes of discussion, purpose as a broad philosophy for life is being treated separately from purposes in living, that is the purpose behind activities of living. This is somewhat artificial in reality for they may be intimately connected; for example, a broad philosophy may give direction to the everyday activity, and life's experiences may contribute to the broad philosophy.
Bell (1985: 482) defines the energy within each person that struggles for meaning and purpose in life as 'spirituality', and sees this energy as a 'unifying and integrating factor of the universe'. Standing alone this definition would appear to imply that spirituality is almost synonymous with the means of finding explanation and purpose of any kind. However, if this were the case scientific search would also be equated with spirituality; but Bell does not mean this for he links spirituality with faith in further defining it as, 'mystery in that it is unknown, unprovable, unmeasurable, and lacks universal definition'.

This understanding of spirituality is closely allied to that of Conrad (1985: 416) who sees it as 'the life principle which pervades a person's entire being and which integrates and transcends one's biological and psychosocial nature'. Spirituality in this sense reflects general dictionary definitions of this concept (e.g. Chambers, 1973: 1303) as a quest for a wide explanation for life and death exemplified by religious and philosophic enquiry. It is used in this way in this section.

The search for spirituality has been linked to the search for security (Berger, 1974); but spirituality may have much more meaning in the lives of people than a means of defence when their own personal security is at stake; for it may have priority over security when people are willing to sacrifice their lives for their beliefs. It is sometimes suggested that the Maslow hierarchy is defective because it does not allow for such extreme choices but while Maslow (1970) chiefly linked spirituality with security he conceded that it could appear in other places in the
hierarchy. It can therefore provide a foundation for life underpinning everything else, and equally well appear as 'self-actualisation' when religious fulfilment coincides with the individual's deepest sense of purpose and identity.

Whatever the motive towards spirituality, many people have throughout the centuries searched for 'pre-ordained meanings' (Elias, 1985), for life and death. Whilst this process exists throughout life, confrontation with serious illness and dying, especially a lingering dying trajectory brings questions of meaning more sharply to focus. At this time patients and those surrounding them, may search for a wide framework of explanation for the situation, and sometimes for religious faith or its renewal (Bell, 1985; Conrad, 1985; Frampton, 1986). Questions which are possible to ignore when all is well, come to the surface in times of crisis. Becque (1960) describes this situation:

'Never has man been able to lead the untroubled life of the flowers or the insects, untouched, undisturbed by the idea of death, the future life, the "other world" and God, the wholly Other. They have come to the point of deciding that this life and matter are all that exists, and that the question can be treated as dead and buried. But though buried the problem of death pushes above the ground again; it is the couch grass, always cropping up on the artificial lawns of our amusements'. (P. 11)
Comfort has traditionally been found in belief in different types of immortality, which is defined as the state of having 'exemption from death' or of 'never being forgotten' or of 'never ceasing to exist' (Chambers, 1973:652). In all of these forms 'immortality' is linked to a meaning for life, for either life continues purposely in some form, or the effect of the life that has been lived and ended remains in the lives and purposes of others, or in the more general purposes of the world. Thus people derive comfort from religious teaching on an after life, from the monuments that are left of their life work, and from a biological sense of going back to nature.

Popa and Hanganu (1979) associate a person's response to dying with the meaning that death has for him or her, and postulate that there are two main, but opposing concepts, one 'tragic' and the other 'positive'. The 'tragic' concept is defined as one in which death means 'total and irreversible extinction - immortality is not possible in any form. Here death is viewed either as 'a desirable solution to the nothingness of life', an 'incomprehensible injustice' inviting a response of outrage, or as 'necessary but without meaning' evoking stoicism. It is not surprising that these meanings of death should be labelled as 'tragic' for they are all forms of meaningless that indirectly apply to the purpose of life as well as of death. For the dying patient with this understanding the suffering of the moment is also meaningless. It is not hard to imagine therefore the anger and sadness which may accompany this view of life and death.
By contrast, all the categories represented in the 'positive' concept are linked to some world purpose; that is a meaning can be applied to human life in that humans have a continued existence in the realm of legend, or their energy becomes part of the boundless life of the world, or of the cosmos. It is interesting to note that Popa and Hanganu do not allow for a distinct after-life for the individual and see such beliefs as purely defensive devices. They thus ignore faiths of many kinds.

Purpose in Life - To Experience and to Achieve

Although some people are able to link their lives to a wide philosophical or religious framework of purpose the separate purposes intrinsic in the varied acts of living are still important. When no such wider framework exists for the individual, and the trend this century has been towards existentialism (Weisman, 1977), then if meaning for living is to be found, it must be found as 'experienced meaning' (Elias, 1985).

The premise that man is a social being has a relevance in this search for meaning, for life is lived in relationships with others and evaluated according to culturally determined values. Elias (1985) maintains that the concept cannot be understood by reference to an isolated human being:

'The meaning of a person's words and the meaning of a person's life have in common that the meaning associated with them by that person cannot be separated from that associated with them by other persons. The attempt to discover in a person's life a meaning that is independent of what that life means for other people is quite futile'. (P. 55)
Life has many needs and purposes, some of them short lived. One relatively stable sense of purpose relates to the individual's sense of identity and of self-fulfilment - of knowing that one is functioning in a way that is true to the self. Maslow (1970) describes the self-fulfilling or actualising tendency as:

'A musician must make music, an artist must paint, a poet must write, if he is to be ultimately at peace with himself. What a man can be he must be. He must be true to his own nature'. (P. 46)

He described some general characteristics of those people he identified as self-actualising; they had a philosophy of life (or religion), exhibited a willingness to learn, and appreciated the 'getting' to a place as much as the 'arriving'. Self-actualisation is therefore part of an on-going dynamic process of development that continues throughout life - since there is always something to be learned the potential is unlimited. Maslow is describing an attitude of mind - purpose as a continuing search as life unfolds.

This concept of continuing purposeful search in Erikson's (1965) stages of human development 'what a man can be he must be' also includes being and becoming more of a human being. According to Erikson this would incorporate achievement at each stage of human development, which at the last, would include acceptance of dying. Rogers (1978) likens the self-actualising tendency to the behaviour of potatoes that he once saw growing in a dark cellar, lit only by a dirty window; their in-built biological mechanism determined that their growth was continually
directed towards this light. Self-actualisation is therefore part of an on-going process and may be stimulated at various points.

Keleman (1974) describes the crisis points in life as stimulators, they are potential 'turning points' in life, that he likens to the growth of a plant whose upward development is circular in nature. It is noticeable that the idea of growth or development accompanies many of the statements related to self-fulfilment. Clinical experience indicates that awareness of dying may prove to be a powerful stimulant to purpose and growth (Mount, 1978), the terminal period can therefore be an important period in life; it is at this time that an all-out effort may be made to achieve something that is of particular importance (Okazaki, 1983). To be aware of self-fulfilment is to be aware of identity. Identity related comments have been differentiated in this study between those that have been provided within the context of esteem and those that are within a context of self-fulfilling purpose.

Confrontation with the ending of life is an invitation to review what life has meant and to evaluate it in some way. It is frequently the experience of those who work with the elderly and the dying that 'life-review' is a powerful tool through which thoughts about life are consolidated. Through this process new understandings may be gained of business that remains to be completed, or relationships that need to be repaired (Babb de Ramon, 1983; Bell, 1985). It may be that at this time changing values soften attitudes, and enable fresh light to be thrown upon previously unsolvable problems. Ainsworth-Smith and Speck (1982) see 'life review' as a bridge between the losses in life and the ability to
deal with them. The final loss in the confrontation with death parallels the others:

‘At every point in life which involves growth there seems to be a need to look and feel backwards’ ... an essential ingredient in managing the change successfully’. (P. 35)

RESEARCH DATA - THE PURSUIT OF PURPOSE

The pursuit of purpose was expressed as important to quality of life by identical proportions of patients in the hospice and hospital. In the hospice fourteen (27%) patients spoke of purpose as important, and in the hospital six (27%). It is not surprising that purpose should feature in a sample of terminally ill patients for as has been discussed, awareness of impending death often stimulates such a search. Of the fourteen in the hospice who were engaged in this search eleven had expressed some awareness of their condition, and four of the six in the hospital. Two main types of purpose emerged. These were:

1. A purpose for life, for living at all - some philosophy for living and dying.
2. A purpose in life - some purpose achieved, or to be achieved or experienced in living,

Purpose as Spirituality - a Philosophy for Life

Having a broad philosophy for life was expressed as important to quality of life by twelve (23%) of the hospice 'random' sample and three (14%) of the hospital sample. For all but one of these respondents this philosophy
was expressed in terms of religious faith, not always Christian; the key concept was faith. In the hospice 'random' sample a higher proportion of women than of men - 27% of women compared with 18% of men spoke of religious purpose; this difference was not noted in the hospital.

Spirituality and the Hospice Venue As noted, a higher proportion of hospice patients spoke of religion than of those in the hospital. It might be expected that there would be references to spirituality in a religious institution such as the hospice which is run by a religious order; for here there were reminders of religious belief in the habits of the Sisters, in religious symbols, and in the services conducted in the wards. Moreover some patients chose to be cared for at the hospice because they were of the same religious persuasion as the Sisters, at least one in the sample chose to come because she had wished to learn something of Roman Catholicism. Mrs F (Hospice) said:

'One of the reasons I wanted to come was because I didn't know anything about Catholicism'.

However, the purpose of the hospice was to take patients who needed their help irrespective of whether they had any religious belief or not, and irrespective of what that belief was. The firm policy of the hospice with regard to proselytising and with regard to providing for the spiritual needs of people of all beliefs was accurately assessed by Mrs A (Hospice):
'It does not matter what your religion is, you are not refused in any way and treated exactly the same - they don't even enquire (if you want to take part). I have no religion. I don't believe or disbelieve but if I had been a Christian that need would have been met here'.

Although religious labels may have very little to do with religious observance or firmness of belief of the individuals concerned, Table (16.1) indicates the formal beliefs of the hospice sample.

Table 16.1 Religious Affiliation of Hospice 'Random' Sample. n=52

<table>
<thead>
<tr>
<th>Religious Affiliation</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anglican</td>
<td>20</td>
<td>38.5</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>9</td>
<td>17.4</td>
</tr>
<tr>
<td>Jewish</td>
<td>6</td>
<td>11.5</td>
</tr>
<tr>
<td>Nonconformist</td>
<td>4</td>
<td>7.6</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>3.8</td>
</tr>
<tr>
<td>None - Agnostic</td>
<td>9</td>
<td>17.4</td>
</tr>
<tr>
<td>Unknown</td>
<td>2</td>
<td>3.8</td>
</tr>
</tbody>
</table>

Spiritual Pain. Considerable spiritual pain was expressed by some patients in the search for faith that was stimulated by their situation; the anguish could be immense. To the child life appears to pass slowly, but once adulthood is established one year follows another in quick succession, and life tends to slip by. It was with a sense of surprise that Mr I (Hospice), in his seventies, found that he was facing the ending of life, and was propelled by his situation into an intense and difficult religious search.
'How can God allow the evil? ... If Jesus was an ordinary man - illiterate - how did he know about things? - This life seems very short - you don’t realise what it is all about until you are well in your forties, and then there is not much left.'

Mr CD (Hospice) was propelled into a search for the meaning behind being rescued from his suicide attempt. He said of this, 'I am not a religious man - or haven’t been - but I have twice been to a service here and feel - yes - there may be a God - someone after all.'

Some patients were searching for a faith that had become lost over the years. Miss LD was one:

'I would like to become nearer to God but am a hypocrite to call on Him now. I don’t know whether God is near or not. I can’t believe in ghosts or fairy stories. If only the Bible were clearer - I only believe what I see is possible and God doesn’t seem possible. God doesn’t seem believable and yet I want to.'

When Mrs J (Hospice) was asked the quality of life question she burst into tears and said, 'You see I have lost my faith and don’t know how to get it back'. (First response)

Mrs H (Hospice) 'Until this - I was born a Catholic and just didn’t bother about it - and now I feel I am going back to it'.
Bell's (1985) definition of spirituality as 'the unknown, the unprovable and the unmeasurable' has a poignant relevance to the situation of these patients for they were honestly trying to come to a belief but the pathway of reason alone was not proving adequate. Their spiritual pain was evident and this was expressed by Miss LD at her second interview:

'I want to believe - but I don't want to come back to the Church on my death bed but I need to come back in my own way'.

Pursuing Spirituality The idea of learning and developing permeated statements on religious faith. Bell (1985) comments on the faith element of spirituality when he states:

'In as much as faith is required to acknowledge spirituality, faith is by definition rooted in doubt and unable to be verified outside of one's own experience'. (P. 482)

The learning and growing therefore comes at least in part from the experience of pursuing. It could be assumed that it is easier to believe in a caring God when everything is going well but when the opposite is the case then faith has to be verified in the adverse situation. None of the four patients who spoke of pursuing and testing their faith in experience pretended that it was easy. The idea of development and challenge predominated in the statement of Mr F (Hospice):
'Being at Mass and singing ... the Mass in general does get to you—you say the words "Lord, say the word and I shall be healed". I won't be healed straight like that—the familiar words hit you in a different way—I have said this for years—they challenge. I have been saying these things and not thinking.'

Spirituality and Comfort Having a faith was a great comfort to some of these respondents. Mrs D (Hospice) was one. In speaking of her quality of life Mrs D (Hospice) recounted her childhood conversion to Christianity and said,

'I was a Jewess and was baptised aged 32. I held my hand until my parents were not here to be hurt. But, from 11 years old I was drawn—from when I was evacuated and crept into a church (at Harvest time) and saw the plaited loaf on the altar. Jewish people eat plaited loaves. It dawned upon me there was only one person—the continuation'.

Mrs D struggled with deep anger at her illness; she had a struggle with her faith but pursued it, and it remained her chief support. On visiting her for the fifth time she was too ill to participate in the research but a member of staff commented that the main thing for her now was the God of her Christian faith.

Mrs C (Hospice) simply said, 'I am up and down a lot—a bad day today (when asked what helps said simply—'God—and the doctors and nurses').
Mrs F (Hospice) was another who found comfort in her faith. At the time of the first interview she was concerned about what would happen to her handicapped child after her death. She could not imagine how this problem could be happily resolved but said,

'I am not worried. I am a Christian and have given it into God’s hands. If I am not there to look after her God will be there’.

By the second interview a series of circumstances had indicated that the daughter was already proving that she could relate to others. Mrs F said,

You worry about things and God takes care of them for you - I was worried about my daughter but God has taken care of that’.

As she slowly deteriorated Mrs F faced sadness and difficulty through which she tested and pursued her faith. She concluded at the sixth interview:

'You don’t need to worry. God does provide for you’.

Spirituality and an After Life Surprisingly, since Christianity has teaching related to an after-life, only one patient spoke of continuing on as an individual. Mrs HD (Hospice) said:

'I believe we shall meet people again’.
This belief comforted her as she mourned the loss of seeing her grandchildren grow up. Another patient whose belief was pantheistic in nature found comfort in becoming part of the on-going purposes of nature after death. Miss ID (Hospice) said:

'Even if I die, that is only like a leaf falling - going back to nature'.

The pain of spiritual search, the pursuit of spirituality and the comfort of faith all indicate how important having a sense of purpose in terms of spirituality was to the quality of life of these respondents - it was a quality of life factor of vital importance to them.

Purposes in Living - Experiencing and Achieving

Purpose and meaning can be related to any activity of living, and are implied in many respondents statements on love and belonging, on having acceptable identity, for example. However, this was implied; the focus in this section is on overt statement on purpose or meaning in life. The key concepts were self-fulfilment, growth and learning in the present as well as the past, in any area of experience, including the spiritual, that was deeply meaningful for the individual. Eight (15%) of the hospice 'random' sample and three (14%) of the hospital sample spoke of various purposes in living as being important to their quality of life. Self-fulfilment had several characteristics - social usefulness, creativity, aesthetic and social pleasures, satisfying occupational or social role.
There were some gender differences seven patients over the two samples spoke of self-fulfilment, or some on-going purpose mainly in terms of social usefulness; six of these were women. Five of these women also talked of spirituality. The emphasis on usefulness may therefore reflect religious directives towards social usefulness as well as social expectations of women as having a caring helping role in society.

Purpose in the Past - Life Review The means whereby past experience was examined for its purpose was through life review. Miss D (Hospice) was one of the women who spoke of usefulness as well as of spirituality. She said,

'God has been good to me - I have had a good life - done lots for other people.'

Mr I (Hospice) talked with nostalgia about his early life on a farm and regretted the lack of self-fulfilment in his later life:

'The animals - the settled Sunday - the feeling that you wanted to go to work - to be with natural things.' He spoke with regret at the change that the death of his parents had made. 'Had to go to town to be cared for by uncle - the poor people who live in places like London don't know what they are missing - wished I had had a career in farming - stayed in the country.'
Mr K (Hospice) engaged in a long conversation about the joys of the countryside and the pleasure that he had gained through holidays arranged by the Council. He then discussed his occupational role and came to the conclusion that it had been a satisfactory choice.

Mr F (Hospice) had a social role as a 'lay religious' and discussed this in terms of personal fulfilment as well as in terms of faith.

'Belonging to a religious order - for twenty years - we are obligated to pray ... when you are saying your prayers it is no longer you and God, but you and God and your mates dotted about.'

Purpose in the Present - On-Going Purpose

One characteristic of many of the statements was a sense of on-going purpose - the need to continue to find meaning in life - in religion, in usefulness, in creativity and learning. For some this was heightened by the awareness that there was not much time left. For example, Mrs F (Hospice):

'I never shall have time now to do everything.'
Continuing to find purpose and meaningfulness in the present was continuing with that which had been purposeful in the past. Mrs F (Hospice) said:

'I used to wake up early - made tea and porridge and took them back to bed - then went out visiting the sick and lonely - still try when I go out for a week-end - it is important'.

She pursued a sense of purpose:

'Sometimes I think what have I come here for - why? - but I think there is a purpose in it - I think why have I come to this place - then gradually see how to use my time - was living alone - but here can do a little - feel more useful here ... I like people am not interested in furniture.' Her satisfaction was expressed in her quality of life measure:

**FEELINGS ABOUT QUALITY OF LIFE AT PRESENT**

Delighted ☒ Terrible

At the moment health better - a little bit more useful'.

At the seventh and last interview, shortly before her death, the first response of Mrs F to the quality of life question was simply, 'Usefulness'.
Mr F (Hospice) the 'lay religious' also took every opportunity to pursue his sense of purpose, although he was extremely weak. He said,

'When the Ave Maria was played (at a concert in the ward) that was a good time for reflection - it's important for you to keep a connection in this way'.

This section on meaning in experience and achievement has largely focused on usefulness because this was the greatest emphasis in the response. For some, part of the continuing purpose of self-fulfilment lay in the arts. Mrs D (Hospice) had a love of music and singing which she pursued. After her fifth and last interview, when she was very weak, a member of staff commented that she was still able to sing a few notes with a nurse. For Mrs A (Hospice), it was being able to continue to draw, for Mr F (Hospice) to continue to write and enjoy poetry. Since the ability to continue to be able to do so depended at least in part on the provision of care they are discussed in chapter 17.

Purpose for the Future - Immortality Life had a purpose if what had been achieved could be carried forward to future generations. The sale of her business held this meaning for Mrs N (Hospice):

'Some result for all the years of my life's work - to hand it to my daughter'.

Purpose as a Pursuit

Strongly associated with the concept of pursuit is that of journeying,
developing and growing. This was a theme expressed by three of the patients. Both Mrs F and Miss D expressed the opinion that learning could continue throughout life:

Mrs D (Hospice) 'Living and learning something new every day'.

Mrs F (Hospice) saw this growth in terms of learning more about religion (as previously noted), and also in terms of learning more about how to be useful. She said of her relationship with another patient:

'I try to smile at her and help her to talk. She is responding a bit, it is important to be useful to people. You can learn right to the end of your life'.

This was the notion of purpose as a pursuit, that was important to quality of life in its own right; one that was to be followed to the end.

CONCLUSIONS
This chapter has discussed the statements of approximately a quarter of each sample, who overtly discussed meaning and purpose in their lives - a sense of purpose was important to the quality of life of patients in both research venues. Part of that meaning was having some over-arching philosophy or religion for living and dying, and was expressed by a greater proportion of patients in the hospice than the hospital. Religious faith was seen as important to their quality of life in the distress expressed when it had been lost, in the intense search to find it, and in the support gained when it was present.
The importance of finding a sense of purpose in the activities of the past and present was seen in life-review and in the pursuit of that which was meaningful and self-fulfilling in the illness situation. It has been noted that women focused particularly on usefulness, and men on their sense of fulfilment in occupational and social roles. Satisfaction derived from the 'aesthetic' and from creativity played a part with men and women. It has been noted that many of the characteristics of these respondents who spoke about purpose and personal satisfaction were those of the people whom Maslow identified as self-actualising (Maslow, 1970); they sought or had a philosophy for living and the pursuit of purpose in all its aspects was important to them, that is, the journeying was as important as the arriving. Their expectations played a part for many anticipated that personal growth and fulfilment should continue to the end of life; and it mattered to their quality of life that it did. In this they expected to be active rather than passive in their living.

A sense of purpose features in some quality of life measures, as 'plans for the future' but meaning in 'life-review', in the 'aesthetic', in being able to continue to learn are not usually found as components of quality of life instruments, although parts may be implied within categories such as that of religious support. For these respondents to omit their continuing sense of purpose, and their means of pursuing it would be to omit a mainstay of life.
Chapter 16 has explored response that suggests that to have a sense of purpose or meaning - an overall philosophy for living and dying, or sense of purpose in the everyday acts of living - was very important to the quality of life of some respondents. In view of the fact that awareness of dying stimulated the search for meaning this suggests that those who undertake the responsibilities of caring for the dying should be prepared to expect and facilitate the search for meaning in all its variety; that this should form an aim of care.

FACILITATING THE SEARCH FOR MEANING

The search for meaning was facilitated in several ways, this was through:

1. Spiritual support.
2. Opportunity to engage in that which was self-fulfilling for the individual.
3. Aesthetic experience.
4. The listening and affirming of others in life-review.
5. Symptom control.
6. Nursing care appropriate to wide needs.

Providing Spiritual Support

Spiritual support in terms of assistance in finding religious meanings, meant a great deal to some of the patients who have been cited in chapter 16. Usually this support took the form of listening and sharing a range of interests, befriending the patient, the listener being prepared to answer questions and provide any specific spiritual help that was
required. It was important that there was no attempt to impose religious answers on the patient. For example, I (Hospice) said:

'There is no religious emphasis here.'

Mr PF (Hospital) said how glad he had been to have the support of the chaplain when he had last been ill, and then said, 'I had seen him several times - very nice he was ... nice to chat to him - he doesn't push religion into you - is very understanding and helpful'.

Patients in both hospital and hospice spoke with gratitude of the support they were receiving from the clergy, and in both venues from religious sisters. Sometimes as with Mr I (Hospice) who was engaged in a painful spiritual search, the spiritual care was intensive:

'A chaplain visits me about three times a day'.

Some patients were very glad to have help that was specifically religious. Mrs PK (Hospital) was very frightened as she was about to have an operation

'X came to see me yesterday - I said to the vicar -. "I am frightened. What can you do, you have got to trust someone?"

This conversation provided her with some comfort for out of it came the trust:
'We are all in God's pocket'.

Mrs D (Hospice) had made it clear that she welcomed specific help in the pursuit of her faith. This was proving valuable to her:

'Sister X kindly lent me some bits of paper (with Bible readings on them) - she does not use the King James version of the Bible - likes Good News - I find it too simplistic. I have been given a Psalm to look at and something in Isaiah and Ephesians. I can look at four lines in all and can comment or not comment as I like'.

These statements indicate that some patients were very glad of professional care in meeting their spiritual pain, and that at least part of this care for them meant a focus on the specifically religious. In her sociological study in the USA of how ministers fulfil that part of their role that encompasses working with the dying, Wood (1975) placed the ministers in one of two categories:

'The ministers I interviewed seemed to orient themselves in one of two ways relative to their view of themselves and of their work: (1) as humanists, or (2) as traditionalists ... each is listening for different kinds of cues, and for each group "being open" is interpreted in a different way.' (P. 142)

Wood explains that humanist ministers tended to see themselves as psychological counsellors, having generally adopted Kubler-Ross' dying stages; traditionalists sought for a degree of spiritual commitment, the
focus being on the sharing of Biblical issues. Wood found that ministers were committed by personal choice, and constraints such as time, to one paradigm or the other, and accordingly their listening became selective to that paradigm. There has been much in the response of this project to indicate the appropriateness of psychological care to dying patients, however the above statements indicate that for some people this is not enough; specific spiritual help must be available if spiritual pain is to be relieved and quality of life achieved.

However, although spiritual help from trained people was important there could also be a need to share spirituality with others. Over and above discussing what was important to them three patients used the research for this purpose; they were not aware whether the researcher had any religious 'leaning' or not. For example Mrs D showed me Psalm 139, and wanted me to share this. We read parts together.

Mrs C (Hospice) provided another example. At the end of her interview she was asked the usual question by the researcher - Can I do anything to help you - ease your pillows or something like that? She replied, 'You could pray for me'. It seemed as if a kind of expectancy hung around the request, and rather diffidently I asked, Now, or later tonight? She replied, 'As you like '. This did not deny that the immediate would have been acceptable, and there was the feeling that this was what was wanted. She happened to belong to a religious sect of which I had no knowledge. However this was not vitally important in the circumstances - a short prayer was made 'to God', and a promise also made to pray later. She was satisfied.
When staff, in their daily work, are prepared to listen to patients talking about spirituality, and to assist within their own limits, they support the search for spiritual meaning. They also contribute to the patient’s sense of well-being and meaning when they facilitate the availability of specialist help.

Providing Opportunity to Engage in the Fulfilling

The patient’s sense of identity formed a reference point in the search for meaning, and as might be expected this was most pronounced when the aim was self-fulfilment. This awareness was a key to their expectations and to the direction that meaning, as fulfilment, took for them. For Mrs N (Hospice) who was interviewed early on in the research before a wide range of interests could be offered through the leisure centre, crafts like, basket making did not fulfil her. She said of this:

>'When they talk about their occupational therapy - making baskets - I don’t want any of that. I can tell what is wrong with a car engine even if I can’t hear it.'

There therefore has to be a variety of opportunities if people are to be able to experience continuing self-fulfilment, as apart from just having an interest to stave off boredom. For Mrs A (Hospice) her continuing sense of self-fulfilment came from being able to engage in her life-time hobby of art, and from being encouraged to do so, this was a theme of two interviews:
'Now that I am getting a little better my wonderful doctor encourages me to draw - the doctor brings me in plants to draw'. (First interview)

'They allow you to use your hobby here - if I had wanted it they would have brought in special paints.' (Second interview)

For Mr F (Hospice) the potential for self-fulfilment came when a poet on the staff gave him the hope of being able to compose once more. The feeling of fulfilment also came when he was able to share his love of poetry with others. He used the research for this purpose. Speaking of the positive aspects of life for him he said,

'Another good thing came up today ... X came who is helping patients to read and write poetry. In the past I published some - Would you like me to read you some'?

He read most beautifully translating directly from the Gaelic - time was forgotten.

An approach that includes helping people to continue to fulfil their deepest needs is not necessarily a problem oriented one; the need may not surface if patients do not have expectations that it can be met. This approach is more a focus on the positive; it provided much more than interest and greatly contributed to quality of life. Attempts to understand a patient's sense of identity can provide care staff with
clues to the ways that they can use their imagination to enhance the meaningfulness of their patients lives.

Providing Aesthetic Experience

The aesthetic in terms of the beauty of nature in the hospice garden and music concerts in the wards and leisure centre brought a sense of fulfilment to some patients, for the inference was that music and beauty had been important to them all their lives. Beauty however, had more than one meaning. Bell (1985), speaks of a relationship between spirituality, meaning, and the arts:

'Out of the well of spirituality spews forth religion, the arts, the poetic, the musical, the philosophical, and the transcendental'. (P. 482)

Two patients expressed this relationship; one day some musicians played in the wards and they immediately met Mr Fs (Hospice) aesthetic needs and his spiritual as well. He said:

'We have had a concert here - cello and double bass - the sound of that - it reaches the depths - gets a tone out of me. If played slowly a kind of religious feeling - an acknowledgement of beauty - of communication - I felt that very deeply - then the flute and the guitar'.
The carefully kept small garden of the hospice assisted too; it provided beauty as well as personal space and a place for quiet reflection. The beauty of an old tree held double meaning for Mrs F (Hospice). At the time of her fifth interview she was beginning to deteriorate, and realised with great sadness that life was nearly ended. She went out into the garden to be alone and sat under an old tree that was slowly dying. As she looked at it she thought,

'I am like that old tree - half dead and dying. But, the tree has a beautiful gnarled trunk so it is still useful - and I can still be useful too'.

A sense of purpose or meaning may come in various ways, provision of beauty in nature and the arts was one important medium.

Listening and Affirming

As noted in chapter 16, when asked to talk about the things that were important to quality of life several respondents used at least part of the interview as a form of life review. This was important to them in eliciting meaning for their lives. Mr PA (Hospital) for example, examined his life and concluded that despite some of its negative aspects he was satisfied:

'I am ... and ... and ... and ... and ... I've enjoyed my life'.

Life review is carried on within the thoughts of the individual and does not necessarily have to be shared; it seemed however in the response that
the sharing was important. The listening of the other provides a sounding board for exploring meaning; accepting listening provides affirmation. One premise of symbolic interactionism is that human behaviour is a response to the perceptions of others. Thus acceptance by others of our personality, our thoughts and feelings promotes growth and is affirming. Rogers (1978) describes the psychological climate that releases the individuals capacity for understanding and managing his life. It contains on the part of others, genuineness, realness, acceptance, caring, empathy, and understanding.

Life-review, was one means whereby these patients were able to find meaning in their lives, and to come to to terms with what had happened in the past as well as what was happening in the present. It was important to their quality of life that living had held acceptable meanings. Patients not only used the research for this purpose but continually used all grades of staff in the everyday interactions with them.

Providing Good Symptom Control

For nearly all of the patients in this section effective symptom control had enlarged their ability to live a life that was more meaningful to them - most made this point. For example, Mrs GD (Hospice) could make more of her life:

'I now have time to pick up correspondence and write letters, so have picked up wider interests. I try to write at least two letters a day - they talk about anything - work, politics. I have had time now to sit back and enjoy my friends - when you are working they get
pushed to the back of your life that is a bonus ... I am getting back the use in my arm and have lost tremor so can write again and do crosswords’.

Providing Nursing Care Sensitive to Wider Needs

Appropriate nursing care, that is nursing care that was appropriate to the wider needs of the patient than to strict physical dependency also contributed to interest and self-fulfilment when there was general weakness. Help with the basic activities of living gave Mrs GD (Hospice) and others more time to concentrate on that which was fulfilling. Miss ID (Hospice) had experienced what it was like to have most of her day taken up with the struggle to live:

‘Am enjoying reading now - the simplest thing at home was difficult and time consuming - putting socks on - impossible’.

Thus nursing care, centred around the patient, rather than dependency priorities also helped self-fulfilment. Frequently in a situation when ‘care’ resources are stretched, the focus is on providing the minimum degree of care that the patient is deemed to need. This policy is justified when it enables patients, especially the convalescent, or the long term chronically sick to regain, or retain, as much independence as possible; for, as discussed in chapter 15 it can be very demoralising to be dependent upon others. However, knowledge of imminent death is likely to alter the values of some, who may prefer to expend their diminishing energies on activities that are more meaningful to them than struggling with the basic tasks of living at home, or in an institution. The ‘extra’
help given with the lower category of needs can bring release to enjoy
the higher, for without this the patient may be too weak to engage in
wider activity.

CONCLUSIONS

The response in this section has indicated how important it was to many
respondents to have a continuing sense of purpose for life and living,
and to share this purpose with others; this was an important quality of
life factor.

Organisation of Care, Expertise in Care, Interaction in Care?

The organisation of care, the expertise in care, and the interactions in
care have all helped to enhance the sense of purpose and meaning in the
lives of these patients. Organisational factors have included flexibility
of living that has enabled patients to be useful to others, and the
provision of a range of creative facilities through which patients could
experience self-fulfilment. Here there have been organisational
differences for all the references to enjoyment of the arts has come from
the hospice with its garden, recreation centre, and provision for music.
These facilities were more than specific to certain needs; for they were
able to meet more than one type of purpose in people's lives. This was
much more than a problem solving approach; for they met needs that had
not emerged as problems. However much we would like to, we cannot
completely know our patients or find meanings for them, but can provide a
range of facilities to maximise the chances of their finding meaning for
themselves.
Expertise has featured strongly in enhancing purpose - the work of clergy and others trained in pastoral care, and able to give both psychological and religious support, has been important in both venues. Experts in the creative arts have enabled the creativity of patients; expertise in musicianship and in management of the garden has brought experiences of beauty; and basically, symptom control, and skilled nursing directed towards wider needs, has enabled patients to make use of everything else. The experience of purpose and self-fulfilment has required a team of experts.

However, it was also in the interactions between patient and staff of all grades and disciplines that purpose was experienced. Johnston (1981) underlined an important function of human relationships when he said:

'It is in relationship with others that I come to know myself, and to realize myself'. (P. 27)

It was in the appreciation, encouragement, sharing and listening of 'the other' that purpose was expressed, explored and affirmed.
CONCLUSIONS
This concluding chapter discusses the many issues that arise from dying patients spontaneous response to the question, What is important for your quality of life today? These issues include the identification of broad quality of life factors and their dimensions, some of which do not appear in quality of life measures; a proposed definition of quality of life appropriate to the care of the dying; organisational influences with regard to the provisions of care, gender differences in coping with terminal illness; and the relevance of the 'sick role' concept to this group of patients. Further issues relate to patients expectations and priorities, and the relevance of past hospital experience to the assessment of the quality of life of the present.

Background to the Project

The aims of the research sprang from the understanding that there was a need in the preparation of quality of life instruments in health care, to identify dimensions of quality of life appropriate to different groups of patients, of whom the dying were one (CH 4). Furthermore it sprang from the awareness that there was a need to improve terminal care (CH 3). Since the aim in terminal care is to maximise quality of life for the patient, information as to what quality of life means for the patient was likely to be helpful. The aims of the research were threefold:

1. The identification of quality of life factors subjectively chosen by terminally ill patients in a hospice and the acute wards of a general hospital.
2. The exploration of the context of priorities, expectations and reference groups within which patients made their response about quality of life, in order to understand the reasons behind their choice of quality of life factors.

3. Application of the findings to the clinical situation. The findings have been related to three concepts developed within a historical context - the organisation of care, the expertise of care, the interactions or relationships of care.

The first two aims will be discussed in turn, but since patients themselves related so much of their response to the clinical situation, clinical issues permeate all of the discussion. This chapter includes suggestions for future research and reflections on this research. It ends with a discussion of the relevance of the findings to some current issues in clinical care.

IDENTIFYING QUALITY OF LIFE FACTORS

Five broad quality of life themes or factors emerged from patients response, these were, having physical comfort, emotional comfort, warm supportive relationships with family and friends, acceptable identity, and sense of purpose in and for life (Figure 18.1). These factors were identified by patients as important to quality of life either because they brought a degree of satisfaction with life when present, or dissatisfaction when absent.
These themes are very similar to those of the Maslow hierarchy of human needs (1970). However, as discussed in chapter 5 this hierarchy was not used as a guiding framework, rather the concepts were those spontaneously offered by respondents. There is a striking resemblance to the hierarchy in the familiar pyramid shape that emerged from the statistics. The broad base reflects the concern of over 80% of respondents with physical and emotional distress and its relief.

The proportions of hospice and hospital patients discussing these themes is very similar - identical in terms of purpose with 27% each, and warm relationships with 73% each. However within these themes there were differences in emphasis between the venues and these will be discussed later.
Figure 18.1 indicates that quality of life for a large majority of these patients, almost at the end of their lives, meant more than simply achieving physical and emotional comfort. These findings are consistent with what is known of human needs (Maslow, 1970), and with the global approach increasingly adopted in devising quality of life measuring instruments in health care. The core domains that Fallowfield (1990) suggests are essential to all quality of life measurement in health care - the psychological, the social in terms of relationships, the occupational in terms of social role and the physical, are all represented here. In addition, having a philosophy for life is overtly featured.

However, the main purpose in identifying quality of life factors was to identify the many dimensions within these broad themes that were meaningful to quality of life. As discussed in the introduction this research was stimulated by meeting an elderly lady - Mrs Jones - for whom social esteem was symbolised by having saved enough money to assure a 'respectable' funeral for herself. It is traditional in quality of life research to place concerns identified as important to quality of life into some form of list as a basis for devising a measuring instrument. Table 18.1 is the list of quality of life factors that emerged from this study. These factors are presented in the form in which they were given in the response; that is as either enhancing or diminishing quality of life. Since patients were so heavily dependent upon others, in their living, it is not surprising that many care factors featured in their comment.
Table 18.1 Quality of Life Components - Enhancers and Diminishers

Mentioned by Hospice 'Random' and Hospital Samples.

### PHYSICAL COMFORT

<table>
<thead>
<tr>
<th>Quality of life enhancers</th>
<th>Quality of life diminishers</th>
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<tbody>
<tr>
<td>Expert symptom control</td>
<td>Distressing symptoms</td>
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<tr>
<td>Prevention of symptoms</td>
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<tr>
<td>Skilled nursing care</td>
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<tr>
<td>Gentleness, skilled positioning</td>
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<tr>
<td>Appropriate well-presented food</td>
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<tr>
<td>Opportunity for choice and control</td>
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<tr>
<td>Explanation, honesty, good communicating</td>
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<tr>
<td>relationship with professionals.</td>
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### EMOTIONAL COMFORT

<table>
<thead>
<tr>
<th>Quality of life enhancers</th>
<th>Quality of life diminishers</th>
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</thead>
<tbody>
<tr>
<td>Opportunity for explanation</td>
<td>Fear/uncertainty/anger</td>
</tr>
<tr>
<td>Appropriate ‘telling’</td>
<td>depression, sadness, shock</td>
</tr>
<tr>
<td>Opportunity to share</td>
<td>Despair</td>
</tr>
<tr>
<td>Opportunity to release feelings</td>
<td>Insecurity</td>
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<tr>
<td>Assurance of symptom control/peaceful dying</td>
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<tr>
<td>Presencing/ empathy/ kindness</td>
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<tr>
<td>Ability to cope - have coping strategy</td>
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<tr>
<td>Ability to find some hopes</td>
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<td>Ability to adjust expectations</td>
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<tr>
<td>Staff availability</td>
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<tr>
<td>Adequate night time care</td>
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<td>Good quality food</td>
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<td>A clean environment</td>
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<tr>
<td>Adequate fire precautions</td>
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<tr>
<td>Interests</td>
<td></td>
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<tr>
<td>Companionship</td>
<td>Boredom</td>
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<tr>
<td>Freedoms- choice and control</td>
<td>Restrictions</td>
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<tr>
<td>Means of escape</td>
<td>Problems of others</td>
</tr>
<tr>
<td>Feeling wanted</td>
<td>Feeling a burden</td>
</tr>
</tbody>
</table>

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## HAVING WARM SUPPORTIVE RELATIONSHIPS OF LOVE AND BELONGING

<table>
<thead>
<tr>
<th>Quality of life enhancers</th>
<th>Quality of life diminishers</th>
</tr>
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<tbody>
<tr>
<td><strong>Ability to remain in touch</strong> - be near family/friends</td>
<td>Separation from family/friends</td>
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<tr>
<td>Facilitated visiting</td>
<td></td>
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<tr>
<td>Privacy possible at visits</td>
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<tr>
<td>Phone contacts facilitated</td>
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<tr>
<td>Receiving from family and friends</td>
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<tr>
<td>Ability to share</td>
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<tr>
<td><strong>Ability to give and support</strong> - make arrangements for others pray for them show concern for them</td>
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<tr>
<td>Family support</td>
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<tr>
<td>Choice and control in decisions</td>
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<tr>
<td>Symptom control</td>
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## WARM RELATIONSHIPS IN THE INSTITUTION

<table>
<thead>
<tr>
<th>Quality of life enhancers</th>
<th>Quality of life diminishers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling wanted and welcomed</td>
<td>Feeling lonely</td>
</tr>
<tr>
<td>Friendly happy atmosphere</td>
<td>Friendless</td>
</tr>
<tr>
<td>Ability to contact congenial others</td>
<td>Without a family</td>
</tr>
<tr>
<td>Developing friendship with other patients</td>
<td></td>
</tr>
<tr>
<td>Developing friendship with staff</td>
<td></td>
</tr>
<tr>
<td>Sense of belonging</td>
<td></td>
</tr>
<tr>
<td>Affirmation of belonging</td>
<td></td>
</tr>
<tr>
<td>Ability to share and give</td>
<td></td>
</tr>
<tr>
<td>Receiving from others</td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td></td>
</tr>
<tr>
<td>Protection/escape possibilities</td>
<td></td>
</tr>
<tr>
<td>Personal space</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| | |
| | |

417
**ACCEPTABLE IDENTITY**

**Quality of life enhancers**

- Retaining sense of identity
- Courtesy and humility of staff
- Acceptable standards of living
  - pretty china - nice environment
- Maximising/maintaining ability
- Maintaining independence
- Feeling care is not a burden to others
- Privacy and acceptance by staff
- Choice and control
- Recognition by others of individuality/
  personality/social identity/name
- Not being treated as a 'saint'
- Opportunity to express individuality
  - give opinions - engage in activity
  of choice
- Not being under-estimated - stereotyped
- Acceptable appearance
- The interaction of others on basis of
  normality
- Having something of which to be proud
  - affirmation of others in listening
- Having opportunity to achieve
  - recognition of that achievement
- Being able to give as well as receive

**Quality of life diminishers**

- Lesser sense of identity
- Being treated as a piece of furniture
- Lowered standards of living
- Diminishing ability
- Dependency
- Feeling a burden
- Embarrassment
- Sense of powerlessness
- Being treated 'as a number'
- Being treated as a 'saint'
- Sense of guilt
- Being stereotyped
- Disfigurement
- Feared stigma of brain tumour

**HAVING A SENSE OF PURPOSE - SPIRITUALITY AND SELF-FULFILMENT**

**Quality of life enhancers**

- Finding purpose
- The ability to pursue purpose
- Religious support appropriate to individual
- Affirmation in listening to life-review

**Quality of life diminishers**

- Lost purpose - spiritual pain
- Sense of meaninglessness
  in and for life
- Sense of aimlessness
DISCUSSION

The identification of quality of life factors shown in Table 18.1 has a relevance for quality of life research and for care of the dying. This will be discussed with regard to:

1. A definition for quality of life appropriate to care of the dying.
2. The 'comforting balancing factors' missing in quality of life instruments.
3. The use of identified quality of life factors in measurement and care.
4. The data and venue differences - organisational influences.
5. Gender and the approach to being terminally ill.
6. Activity and control and its relevance to the sick role concept.

A Definition for Quality of Life Appropriate to the Care of the Dying

One of the major characteristics of Table 18.1 is that it is presented in terms of the positive and the negative - the enhancers and diminishers of quality of life. This is perhaps somewhat surprising since it was based on response to the question, "What is important to you today for your quality of life?", which would seem most likely to elicit the positive. Table 18.1 reflects many negative as well as positive comments made by patients, for advancing illness had brought much experience of loss into all aspects of their lives. Quality of life for them, meant addressing the negative as well as building upon the positive.

As discussed in chapter 4, quality of life is a most complex concept that is defined differently according to the purpose for which it is to be
used. In some quality of life measuring instruments it is implicitly defined as a collection of factors that people possess to varying degrees. For example the Karnofsky Index (Karnofsky, 1948) focuses on levels of physical ability, the Spitzer Index (Spitzer, 1981) on levels of activity, performance in daily living, health, support of family and friends, and positive emotional outlook. Such an approach is useful to clinicians in trying to improve the low score items and build upon the high.

The focus of other instruments, for example, the Nottingham Health Profile (Hunt and McEwen, 1980), is on the negative aspects of experience, implicitly defining quality of life negatively in terms of valued factors that people do not have. Such an approach identifies problems but not factors that contribute to well-being. Other instruments (e.g. Selby, 1984) measure both positive and negative factors. A completely different approach to quality of life is that of Calman (1983) who focuses on the expectations that influence the choice of quality of life factors. As discussed in chapter 4, and later in this chapter, this approach is useful in terminal care, in helping patients adjust health expectations to the reality of advancing disease, and focus on different hopes.

The data in Table 18.1 suggests that any attempt to measure the quality of life of the patients in these samples should include a positive as well as negative approach, for both featured so strongly in their comments, and illuminated areas to build upon as well as relieve. However, for dying patients, the time comes when it is no longer possible
to boost valued factors such as mobility, or to remove the source of problems that lie with the advancing disease. The emphasis is then on trying to bring some comforting elements into patients' lives. Many comforting factors, such as the empathy of staff, their friendship, cheerfulness, and willingness to help without letting the patient feel a burden, were strongly emphasised in the data as having a very positive weighting value in quality of life assessment (CH 11 particularly). The meaning given to them by patients was that they helped, often to a marked degree, to balance the negative with the positive. The focus therefore needs to be on the factors within, and over, all dimensions that have a positive effect on total life assessment. These are the comforting factors.

The following definition of quality of life could therefore assist carers not only to build on the positive and reduce the negative, but also search for extra factors that would enhance their patients' lives by bringing comfort, and in so doing, influence its overall assessment. The weighting given to quality of life factors is likely to be unique to individuals.

Quality of life is the balance of a weighting between quality of life enhancers and diminishers, to which individuals give different value.

Comforting Factors - A Missing Dimension in Quality of Life Instruments
There are some factors in Table 18.1 that were of major importance to patients, that do not appear regularly, or at all, in existing quality of
life instruments. These all related to emotional comfort and are, having 'appropriate' information about the illness, finding comfort in the assistance of staff, and finding comfort in interaction with staff.

Having Appropriate Information As discussed in chapter 10, having information about the prognosis was very important to patients' quality of life since it formed the basis of hoping and coping. The need for information, the kind and the amount required was unique to individuals. Information was only appropriate to each patient when it was honest, and as comprehensive as he or she wanted, but did not go beyond this. Existing quality of life instruments often include measures of the patient's approach to the illness and levels of coping, but not, it appears, any measure of their satisfaction with the degree of information received, upon which hoping and coping rest.

Comfort in Being Assisted One comfort that does not feature in existing quality of life instruments is the degree of satisfaction that is obtained from the 'assisting' activity of nursing (Henderson, 1960). In that physical comfort is recognised as important then basic nursing care is implied, but not necessarily the many helping acts undertaken by nurses that compensate for the patient's weakness. Assistance of this kind was valued highly by patients in this study (CH 11) for it comforted the distress of helplessness and helped to make life worth living.

Comfort in Interaction with Staff Relationships with staff were vitally important to the quality of life of patients in every section of the response. Some types of interaction, such as skilled counselling are part
of expertise, but it is not these which are considered here. Rather it is a form of interaction between carer and patient very similar to the attitude in care which in chapter 1 has been called a 'spirit of care'. The qualities in the interaction of staff with patients that were so important were empathy, gentleness, courtesy, naturalness, friendliness, cheerfulness, and a form of shared humanity in which the carer did not stand at a distance on some sort of professional pedestal.

These qualities of interaction were therapeutic in themselves; they helped to build up trusting symptom control relationships, comforted emotional distress, helped dependent people not to feel a burden, and provided an environment in which the lonely, often isolated from family and friends, could find new friendships and a sense of belonging. They contributed to the sense of value that patients had of themselves in the perception of the value given to them by others, and to the sharing of purpose that affirmed that which was most meaningful to life.

These qualities of interaction were important to patients in both venues and important in relationships with staff of all grades and disciplines. Interaction between staff and patient, even though brief at times, had potential to enhance or diminish quality of life over considerable periods of time. Yet, quality of relationships with professional carers do not appear to feature overtly in existing quality of life measures.

There may be many reasons for this omission; doctors, nurses, and the public may not fully recognise the importance of these qualities to the well-being of the dying patient, and may have been traditionally blinded
to the relevance of staff patient interaction for patient well-being. Chapter 2 discusses the distancing of the doctor from the patient with the onset of the scientific era. Distancing was supposed to produce objectivity - a 'panoptic gaze' (Armstrong, 1983), in which variables in the patient's situation could be manipulated without being influenced by the manipulator. For this group of patients at least, this is an illusion - the distancing and coldness of professionals had one effect, the warmth of their presence another. It is more, rather than less, scientific therefore, to take interaction into account in measuring patients' sense of well-being.

In the importance given to technological, rather than bedside aspects of care, nursing has often failed to appreciate the potentially therapeutic effect of nurse patient relationships; although some interactionist models of care have been developed (e.g. Peplau, 1952; Travelbee, 1971). Poor staffing levels often make it hard for nurses to concentrate upon anything but tasks associated with physical care and the support of medical intervention. Nurses do not automatically see the patient as deprived when their interaction with patients is restricted in such circumstances. As James (1986) noted, even in a hospice type institution, junior staff did not equate emotional 'care' with 'work'; although they recognised that it had a value. The corollary is that when the physical tasks are completed the work is complete. It is difficult not to use this as a defence when under pressure. In addition this gives a sense of achievement.
In exploring the reasons why 'caring' - the companionship and emotional support of nurses - seems to be a hidden value, Vaughan (1990) suggests that not only do nurses not recognise its importance but that patients may find it hard to talk about, so that it is not accorded public recognition:

'Can you imagine someone going to the pub or returning to work and talking about the care they received from nurses? They will talk about 'my operation', 'the pills which the doctor gave me which help my blood pressure'. It seems much less likely that they will mention that a nurse held their hand when they were frightened; that they cried and were offered comfort. These sort of things just don’t get talked about in public. Not only do they not get talked about but they may be hidden in the recesses of memory. Regardless of their significance at the time, recall may be too painful a reminder of human frailty'. (P. 46)

In chapter 4 (p. 86) Spitzer (1981) is quoted as casting some doubt as to the sensitivity of his instrument to the dying. He suggested that it might have some unrecognised defect, or that there might be some underestimation of the ability of the human mind and spirit to compensate for major infirmity. The data in this study suggests that he is right on both counts; one missing factor centres around the comfort inherent in relationships in care which helped bring some positive factors into lives that had high amounts of negative. These comforting factors then boosted patients' ability to cope with their infirmity.
Whilst contact between professional and dying patient has been recognised as important in many ways over the years (e.g. Strauss and Glaser, 1977; Feigenberg, 1980; James, 1986) it has not been recognised sufficiently in the field of quality of life research to appear as a dimension in measuring instruments. Fallowfield (1990) describes 'quality of life' as a missing measurement in health care, this study suggests that the 'comforting balancing factors' are an important missing dimension in that missing measurement.

The Use of Identified Quality of Life Factors in Quality of Life Measurement and in Care

As stated in chapter 4 it was hoped that this project would be useful to quality of life research in illuminating new dimensions for measurement, rather than devising the measures themselves. However, since the dimensions in Table 18.1 were derived from patients' satisfaction with life, implied in the quality of life question, it might be suggested that the simplest and most appropriate measures would be those associated with patient satisfaction. Many of the factors in Table 18.1 were directly related to care, some of these could also feature in evaluation that centres on input, process and outcome in health care.

As discussed in chapter 4 the more comprehensive a measuring instrument becomes the harder it is to manage, especially when patients are weak. It is suggested that parts of a measure could be used or developed with small groups of patients within a total group. This would not provide a global quality of life assessment for each patient, but would help to
indicate quality of life experienced by a group of patients, such as those in a ward.

Whether a measure is useful or not depends to some degree on the stability of the factors within it over time. Through repeat interviews in the hospice sample it was possible to gain some illumination into whether quality of life components chosen by patients, remained stable over a few weeks. One major finding was, that once basic comfort needs were met, then patients could become aware of higher needs of belonging, esteem and purpose. In this sense therefore, when there was deprivation of comfort followed by relief, what mattered to the patient did not remain the same. However, there was a stability over time among the dimensions of the higher needs when comfort was maintained. This was found in all twenty-seven repeat interviews and no inconsistency was noted.

What is considered appropriate to quality of life is likely to vary over time with changing expectations. New possibilities may arise with new discovery; what is considered feasible or 'a right' may change with changing attitudes and economic conditions. In the last part of this century, for example, there has been some emphasis on personal fulfilment which, in its extremes, is now being criticised as damaging to society as a whole (Ehrenreich, 1983). A quite subtle change in attitudes such as this, or a greater emphasis on 'the economic' in health care could influence whether public money is spent on helping dying patients to experience self-fulfilment in their last days, or on buying pretty china to enhance self-esteem.
Finally, the use of these factors must relate to their use with individuals. Here the quality of life instrument is somewhat blunt for it stems from consensus. There has been much consensus in this study; the same quality of life factors emerged time and time again until they ceased to cause surprise. However, the fact that the 'respectable' funeral, so important to Mrs Jones, did not, is a reminder that individuals are unique. It is hoped that this thesis will be useful in the care of the dying, not only in enhancing awareness of the likely concerns of patients, but in stimulating carers to look for the unique in each patient encounter.

The Venues - Similarities and Differences - Organisational Influences

It was not one of the aims of the research to directly compare the hospice with the hospital, but rather to identify whether dying patients in these very different organisational settings had similar conceptions of quality of life. As indicated in Figure 18.1 the same broad quality of life themes emerged in each venue; and statements made by patients in both venues were often similar. Physical and emotional comfort and the 'comforting factors' discussed in chapter 11 were important in both institutions. Similarly contact with family was valued by most. Acceptable identity mattered in the same way in both venues as regards the need for courteous staff, and the need to retain choice and control, and as much individuality as possible. For some patients in the hospice, esteem was associated with being in surroundings of high standard. Purpose in terms of religious faith was important to some patients in both venues.
Some major differences between the venues were found in the emphasis given within the themes of love and belonging and purpose. These reflect different organisational aims. The acute ward of the hospital was not viewed by patients as 'home' - it was not a place of belonging; rather it was a temporary place of treatment, from which it was usual to return home or to some other institution when all that could be done had been done. The aim of cure or improvement in the hospital was also reflected in the difficulty experienced by some patients in obtaining information as to their prognosis. Since the emphasis in the hospital was on treatment there appeared to be little provision for patients to live more fully in terms of activities and interests that might contribute to a sense of purpose and self-fulfilment - a significant proportion of patients expressed intense boredom.

In contrast the aim of the hospice was to provide a home for patients and sense of family belonging, a place where people could live out their lives as fully as possible - and this aim was overtly expressed by staff and in the recreational facilities available. The sense of belonging was very important to some patients who knew that they would never go home, and the interests brought meaning into life. One cannot automatically assume, however, that any of the hospital patients would have preferred to have been in a hospice type setting; as indicated in chapter 8, two hospital patients were distressed at the thought of being moved to another institution, away from friends and familiar surroundings. In these circumstances the acute ward might win in a trade-off situation. Rather, there would seem to be a need to bring some of the elements of
fuller living into the hospital situation and so enlarge its aims of care, to encompass more fully the higher needs.

Gender and the Approach to Terminal Illness

Throughout the findings it was noted that in all the broad quality of life themes apart from that of physical comfort women were more expressive than men. A larger proportion of women than men in each sample talked openly of dying or of being chronically ill, and of their emotional response to this situation. Men often exhibited initial repression of feelings which then broke out with intensity. Women spoke more of finding the empathy of staff and friendship of other patients a comfort, whilst the complaints about other patients were made by men. However, men made some of the most intense statements with regard to family love, and to being separated from home.

These findings of gender differences may reflect the expressive role of women associated with a nurturing role enabling them to show their feelings more easily and openly (Parsons and Bales, 1955; Oakley, 1974). Added to this, expression of feelings is likely to be made more difficult for men because of social expectations inculcated from an early age, that men should be brave and adopt a 'stiff upper lip' in face of trouble. The lesser ability of men to share feelings denied them this comfort and diminished quality of life in that the men who were most repressed were also the most miserable. A stiff upper-lip is not ultimately conducive to emotional comfort. Men however, spoke much of the physical care of nurses, and of eventual friendship with them. This places nurses in a good position to comfort by assisting men to express their feelings.
Activity and Control and its Relevance to the 'Sick-Role' Concept

In chapter 5 it was noted that the Parsonian 'sick-role' concept (Parsons, 1951) was not appropriate to patients who were chronically ill. Release from social obligations and passive compliant behaviour could be seen as beneficial for the patient and society - an acceptable bargain when cure was the outcome, but had little to offer in chronic sickness. Thus it was considered that there was a need for new 'sick-role' formulations (Levine and Kosloff, 1978) in this situation.

Some years ago many terminally ill patients would not have been able to be anything but passive recipients of care in the last weeks of life, for pain and weakness would have reduced them to a state of heavy mental and physical dependence on others. Their aim would have been more that of trying to endure rather than that of living life more fully. Advances in symptom control have made an enormous difference, enlarging patients' expectations, as to what they can do, or would like to do. Among the patients in this study, whose physical and emotional distress had been eased, and who were not overwhelmed with weakness, there was an emphasis on the importance to quality of life of taking some active control in treatment and care; and engaging in as many activities of life as possible, including giving as well as taking.

The history of scientific advance has been discovery followed by the generation of new expectations. For example, the ability to combat renal failure with dialysis or transplant engenders expectations, on the part of professionals and patients alike, that these techniques will be used, and the patient restored to as normal a form of living as possible.
Symptom control also enlarges the potential for living, bringing new hope and energy to the patient. Not to make provision for this living is to leave patients just waiting to die in a state of frustration which is most diminishing to quality of life.

It could therefore be argued that the ability to relieve symptoms should be related to an obligation to assist the patient to use restored energies to live life to the full. The 'sick-role' characteristics then become inappropriate. These findings suggest that passivity and compliance need to be replaced with opportunity for supported activity, and control for the patient - a 'supported living role', the role of the professional being changed from one who does the controlling to one who offers the support.

QUALITY OF LIFE FACTORS IN THEIR CONTEXT OF PRIORITIES, EXPECTATIONS AND REFERENCE GROUPS

The context of priorities, expectations and reference groups within which respondents presented their quality of life factors illuminated the reasons behind their choice of these factors. They related to:

1. 'Quality of life' priorities of patients and the Maslow Hierarchy.
2. Reference to the past and quality of life assessment - other hospitals.
3. The role of expectations.

Quality of Life Priorities and the Maslow Hierarchy

The importance of the priority of the basic needs of physical and emotional comfort to awareness of the higher needs in the Maslow
Hierarchy (Maslow, 1970), began to emerge as patients talked of being overwhelmed by physical or emotional pain, and of how its relief brought the ability to live more fully again. When the characteristics of the respondents whose comments at interview remained entirely within the bounds of the basic needs, were examined, it was found these were the patients who at interview seemed sunk in shock or a state of misery and unable to think of anything else (Table 18.2). This table suggests a relationship between meeting the basic needs and the ability to move to higher needs. It also indicates that men were more overwhelmed than women, and emphasises the importance of good symptom control and emotional care.

<table>
<thead>
<tr>
<th>Concern only with physical/emotional factors</th>
<th>Hospice</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>m</td>
<td>f</td>
<td>total</td>
</tr>
<tr>
<td>32</td>
<td>10</td>
<td>19</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Concern with higher factors also</th>
<th>Hospice</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>m</td>
<td>f</td>
<td>total</td>
</tr>
<tr>
<td>68</td>
<td>90</td>
<td>81</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Totals</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>m</td>
<td>f</td>
<td>total</td>
</tr>
<tr>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>n</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>m</td>
<td>f</td>
<td>total</td>
</tr>
<tr>
<td>(30)</td>
<td>(22)</td>
<td>(52)</td>
</tr>
</tbody>
</table>

Whilst it was thought that Maslow's hierarchy of needs would be relevant to analysing the data, since many health care professionals were familiar with this theoretical model, it was not originally considered that the data would validate or verify any part of the theory. In writing the
Preface to his theory of motivation Maslow (1970) expressed some concern that he had not been able to test it in a laboratory situation. He said:

'It is fair to say that this theory has been quite successful in a clinical, social and personological way, but not in a laboratory or experimental way. It has fitted very well with the personal experience of most people and has often given them a structured theory that has helped them to make better sense of their inner lives ... And yet it still lacks experimental verification and support. I have not yet been able to think of a good way to put it to the test in the laboratory. The lesson I had learned from this ... was ... when we talk about the needs of human beings, we talk about the essence of their lives. How could I have thought that this essence could be put to the test in some animal laboratory or some test tube situation? Obviously it needs a life situation of the total human being in his social environment. This is where confirmation or disconfirmation will come from'. (P. XII)

It is suggested that some small confirmation has come from these samples of dying patients who were grappling with a disease that had an impact upon their total being within their social environment and had reduced them to a sharp awareness of the importance of the basic needs.

Reference - the Past and the Quality of Life Measure

The main reference against which quality of life of the present was evaluated was the experience of the past. As noted in chapter 6, quality of life assessment could rise suddenly and dramatically with the relief
of pain. This suggests that assessment can fluctuate considerably with changes in situation such as these. This queries the usefulness of quality of life measures such as Spitzer (1981), that have been used to assess the quality of life of periods such as a week in one single assessment, for the result may not accord with the reality of experience in that time.

Other Hospitals. One unexpected outcome of the research was the reference to past hospital experience mainly by hospice patients (Table 18.3):

<table>
<thead>
<tr>
<th>Dimension - Hospice better</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Friendliness and kindliness</td>
<td>12</td>
</tr>
<tr>
<td>Choice and control</td>
<td>3</td>
</tr>
<tr>
<td>More time for patients</td>
<td>3</td>
</tr>
<tr>
<td>Physical care</td>
<td>4</td>
</tr>
<tr>
<td>Quietness - small bays</td>
<td>3</td>
</tr>
<tr>
<td>Cleanliness</td>
<td>1</td>
</tr>
<tr>
<td>Better - non specific</td>
<td>4</td>
</tr>
<tr>
<td>Dimension - hospice same</td>
<td></td>
</tr>
<tr>
<td>Friendliness</td>
<td>1</td>
</tr>
<tr>
<td>Dimension - hospice not so good</td>
<td></td>
</tr>
<tr>
<td>Friendliness</td>
<td>1</td>
</tr>
<tr>
<td>Provision for single room</td>
<td>1</td>
</tr>
<tr>
<td>Too quiet - small bays</td>
<td>1</td>
</tr>
<tr>
<td>Soup</td>
<td>1</td>
</tr>
<tr>
<td>Routines</td>
<td>2</td>
</tr>
</tbody>
</table>

* Comment made by 25 (48%) patients. Some made more than one comment.

The detailed comments behind these statistics have been noted in appropriate sections - they paint a very poor picture of some of the care elsewhere, particularly as regards the interactions of care. This indicates the need for improvement if quality of life is to be the aim.
for patients. The hospice was not only most often seen as good in its own	right but also because it compared so favourably with the institutions
experienced in the past.

The Role of Expectations
A variety of expectations were overtly offered by patients. Health
expectations were basic to hoping and coping strategies, since they were
a response to the patient's perceptions of the situation. One means of
gaining comfort was to reduce expectations. The result of not knowing
what to expect as regards the prognosis was fearful uncertainty. The
result of having expectations of 'getting better' too abruptly or
prematurely removed was shock and often the inability to know what
mattered to quality of life.

Expectations also related to age; the younger patients felt more deprived
of lost years and grieved the loss of physical prowess and occupational
role; elderly patients could comfort themselves that they had had a full
life. Expectations also dictated whether patients' felt a sense of hurt
or injustice in their situation - injustice was particularly felt if
doctors, nurses, or family - fell below expectations of their role. When
the conditions of living in the institution were much lower than expected
there was a sense of being downgraded - quality of life was diminished;
when they were as high or higher than expected, quality of life was
enhanced. None of the expectations expressed by patients were
particularly high, they did not expect any great luxury; expectations
could sometimes be very low, as seen in the patient who did not tell the
staff of her pain because she did not expect that they could ease it.
Priorities, reference groups and expectations were offered spontaneously by patients in order that their opinions should be understood. It is suggested therefore that it is necessary to know something of patients' expectations in order to understand them in their situation. Such understanding can be used to increase sensitivity in approaching issues of prognosis, as well as used as a guide to what matters in care. Since these influencing factors arose spontaneously in response to the quality of life question, it is suggested that a similar question, used discreetly and not too frequently would elicit similar response. Although without the same confidentiality that was offered in the research patients might wish to hold back some information.

The importance of quality of life definitions to providing a guiding framework in care has been discussed earlier in this chapter, and a definition proposed. The importance of expectations in the data suggests that the definition offered by Calman (1983) is also very useful:

'Quality of life measures the difference at a particular moment in time between the hopes and expectations of the individual and the individual's present experience' (P. 2).

Reflections on Research
These findings can be generalised to the population from which they were drawn, but even here there must be reservations, for the hospice sample was quasi-random and the hospital sample a convenience one. However there was a consistency of findings between the two samples, in quite different settings, and the findings accord with well known needs theory (Maslow,
1970), and as far as the broad factors that emerged, with the global approach adopted in recent quality of life studies.

The staff interview and staff meetings were used in the hospice as a form of 'triangulation', no inconsistencies appeared as to what mattered to patients, although much more information was obtained from the interviews. Similarly no inconsistencies were found within interviews or over the series of interviews with some patients.

The samples represented older patients with no-one under forty, it would have been interesting to compare these findings with the comments of some younger patients who were terminally ill. These samples also represented the 'fitter' of dying people, although many died within a few days of interview, those less fit were unable to be interviewed. If they had been included it is likely there would have been less emphasis on activity and control.

In chapter 5 ethical issues were discussed. It was important to protect the patient. Approximately a quarter of hospice and hospital patients made some comment indicating that the research had been helpful to them. Of these, eight (15%) of the hospice 'random' sample, and two (9%) of the hospital sample requested further interviews and a further eight (15%) of the hospice 'random' sample and four (18%) of the hospital sample said how pleased they were to have had the opportunity to have talked. No complaints arose out of the research.
FINAL CONCLUSIONS

The findings of this study indicate that quality of life for these dying patients was global in nature; commensurate with living as full and as normal a life as possible. Since patients were relatively helpless, whether this was feasible or not depended on others. If life was to be lived more fully, and with satisfaction, then there had to be provision to do so, expertise in dealing with physical and psycho-social problems, and also interaction with staff that was based on mutuality, empathy and at least some opportunity for the patient to take control. These findings affirm what are recognised today as good principles of terminal care; the question raised in chapter 3 was how far these principles, instituted by hospices, could be extended to other settings. Adaptation is considered here as it relates to organisational provision, expertise and interaction, and finally to the overall organisation of care.

Organisational Provision for Fuller Living

Provisions within the institution - its opportunities for freedom and choice, its recreational facilities influenced how easy it was to live life as fully as possible. Absence of close restrictions enabled ambulant patients to roam relatively freely, find places to have privacy with relatives, stay up when they liked, meet others who were congenial, and make the best use of the facilities that were available. The hospice was able to offer this freedom to a marked degree in accordance with its philosophy of the institution as home. Freedoms were also found in the hospital ward, as one patient stated it depended very much on the sister in charge - issues of personality, differing attitudes to control for the patient, and the needs of other patients are all relevant.
The recreational facilities of the hospice were important, but it is not easy to make provision for recreation when this involves large capital expenditure. More use could perhaps be made of occupational therapy departments that already exist, of voluntary bodies such as 'Music for Hospitals', and individual volunteers, to bring interests into hospitals. The family might be encouraged to bring hobbies, and partake in them with the patient. Sharing hobbies or being able to talk about them is one means of maintaining a bond between the patient and the family, when there seems little else to discuss than the encroaching illness. A patient in the hospice was able to find much to share with a niece who visited her, in discussing the poetry that she had been encouraged to write. The memory of such sharing can also be a comfort in later bereavement. It meant much to patients in the hospice and their relatives that ward staff were supportive of these interests.

Expertise
As has been discussed in chapter 4 intense efforts have been made to improve symptom control through professional education and through the provision of teams of experts who may be consulted. Some hospitals already provide symptom control equal to that of major hospices. As professional expectations rise as to what can be done there seems no reason why improvement should not continue, particularly if these expectations include an emphasis on prevention, and on the appropriateness and acceptability of readily consulting others, within and without the hierarchical team, when in difficulty.
Skilled nursing is important, for nurses not only bring their own skills in physical and emotional care to the patient but co-ordinate those of others around the patient. The 'basic' skills of nursing - the expert gentle handling of the patient - the careful positioning - were very important to many of the patients in this study. The degree to which these skills of experienced nurses are directly available to patients will depend to some extent on how highly the nursing profession values 'basic care', for so often it is deemed to be the province of the most junior members of the team (Salvage, 1985; Field, 1989). It will also depend upon how nurses manage this alongside the pressure of work that is more technological, or more administrative in nature.

The current emphasis on individualised nursing systems such as Primary Nursing (Manthey, 1980; Department of Health Nursing Division, 1989; Wright, 1990), has potential for closer contact between skilled nurses and patients. With the advent of Health Care Assistants decisions as to the 'skill-mix' needed in wards (DHSS Steering Group, 1986: Clark and Gorton, 1990) are important; whatever mix is chosen it will be necessary to ensure that there are sufficient nursing skills available to the patient over twenty-four hours.

Expertise of many kinds enhanced the quality of life of patients in this study. In addition to meeting physical and emotional needs it included help with family and social problems, and with finding meaning and purpose in life. It was all so necessary in enabling patients to live fuller lives. Adaptation therefore requires a full team of professionals engaged in helping the family with the patient, as part of the unit of
care. However an emphasis on expertise has its dangers if expertise is thought to be all that matters. This then becomes another form of technology to be applied to the patient (Twycross, 1986: Field, 1989).

**Interaction in Care** The relationships in care between patients and staff that brought so much comfort to patients were found in the busy hospital as well as the hospice; this was emotional care that was spontaneous and informal in nature. This kind of care is very vulnerable for it is the least visible part of nursing work. It does not currently have the status of expertise, and is therefore more difficult to justify or defend. Moreover, it is not easy to build relationships with dying patients when hampered by the fear of death or when task centred approaches to care divide the patient's needs between many people. Pressure of work is perhaps one of the greatest dangers for it severely limits time available to patients, making it hard for even the most willing of staff to give cheerful relaxed care. The ever increasing demand on health services and the current financial constraints increase this pressure.

To these difficulties may be added the tensions that exist for the professional in relationships with patients. Hockey (1979) outlines these in relation to nurses but they apply to all health care professionals. There is the conflict between the carer as a person and as a professional - patients in this study valued naturalness and spontaneity. There is conflict between professional distancing and becoming emotionally involved - patients valued close relationships. Conflict exists between activity based on scientific knowledge and care as an expression of human compassion - compassion and empathy were valued highly. Finally conflict
exists between loyalty to orders and to conscience, and between a
conspiracy of silence and the need of patients and relatives for
information - the latter is particularly important to the dying.

There is thus a great deal in the current situation to hinder the
development of the type of interactions so important to the quality of
life of patients in this study. Personal observation over some years
suggests that unless staff are members of a team that encourages such
interaction, it is the junior members of all disciplines, who have not as
yet been clothed with the full mantle of professionalism who are best
able to engage in relaxed relationships, together with some who have
experience enough, and status enough to lay that mantle aside. These
problems faced in interaction with patients suggest that three factors
could assist gradual improvements in relationships. These are better
recognition of the importance of everyday interaction to emotional care,
provision of time for such care, and emotional support of staff.

Recognition of the importance of interaction in health care for members
of all disciplines, stems from an awareness that interaction contributes
positively and negatively to the well-being of the patient - it is not
neutral. The starting point would seem to be in basic education, when
these issues could be explored. In nursing, models based on human needs,
and those on interaction emphasise the needs of people as social beings,
and the importance of interaction - a sociological input is important. So
also is greater theoretical understanding of the dying patient's
emotional needs (Slevin, 1990). Professionals also become aware of the
expectations of their role from organisational guidelines, such as job
description. Whilst, in nursing, regular reference is made to research and issues of management it is queried how often or how overtly reference is made to the responsibility for therapeutic interaction between nurse and patient. Recognition here would place emotional care as part of 'work', rather than as an addition to work (James, 1986).

It is no good however, having expectations of emotional care and not recognising that this takes time. Much of the emotional care so important to patients was received as part of physical care; at the least therefore, staffing levels should enable this care to be carried out in a relaxed way. However there are many patients who are relatively independent and do not need the kind of physical care that ensures close contact with the nurse. If they are not to be left out then time needs to be set aside to talk with them. Moreover emotional distress is not always expressed at times convenient to the nurse - nurses in the hospital stopped what they were doing to cuddle a patient - a sister in the hospice came to provide a shoulder to cry on. Additional flexible time needs to be built into the day to meet such needs. Towards this end research directed towards developing criteria for measuring workload is important (Fittall, 1990).

Some re-allocation of tasks would enable more time to be spent with patients. Some patients in the hospital felt that nurses were undertaking tasks that others could do. James (1986) records nursing auxiliaries as feeling that they did not have enough time to meet patients' emotional needs. A glance at their worksheet indicates that this included cleaning
sluices, buttering bread, and cleaning cupboards; activities that could have been undertaken by staff who were not members of a nursing team.

However, some of these activities at least provided respite from their 'emotional labour' (James, 1986). In their close contact with patients nurses bear the chief responsibility for the relationships so important to emotional care, and bear the repeated loss of patients they have come to love. If they are to continue to give emotional care they need early on in their education to explore issues of dying and their own reactions to it, and to be able to release their feelings with the support of peers and of management. The retreat to the linen cupboard or its equivalent, needs to be accepted, rather than denied or frowned upon. If the change to individualised systems of care becomes more general, the need for emotional support is likely to increase.

The Overall Organisation of Care

One of the factors that made the early hospice care effective was that management and carers worked under a single philosophical framework that ensured that they held the same values, uniting them in their aims, simple though they were. The same framework was reiterated at the beginning of the modern hospice movement although its aims were more diverse. The emphasis was on a unified inter-disciplinary team, the well-being of the individual patient being the central value and pivot of the organisation. This suggests that consensus within the organisation as to aims and values is important to good care.
The health services of today are characterised by conflicting values of many kinds, between disciplines - administrators - health professionals - and within disciplines. Economic values are increasingly set against care needs, different values may be accorded to different specialities, and to different types of patient; instrumental activity have different value from the expressive. It is much easier for an institution with a single aim, to be clearer about the principles that should be supported by all. However terminal care principles also sprang from strong underlying philosophy that aided clarity, defining such issues as the view that carers had of themselves, of patients, and of their work and relationships with them. The fact that the same religious philosophy may no longer be seen as relevant to a large proportion of people today does not mean that a carefully worked out unifying system of values is not needed in health care. This need is recognised in nursing models as they seek to address such values. From an existentialist stance Johns (1990) states that two significant issues arise for nursing:

The first is that there are no universal truths for nursing practice. Second, nurses need to identify for themselves what is important in their nursing lives, for them to make sense of what they do. The implication is that without such order there can only be chaos. It would seem axiomatic that practising nurses have a clear understanding of what they are trying to achieve in order to give direction and cohesiveness to the common task of meeting patient needs'. (P. 2)
Since no one discipline works on its own, cohesiveness of values is ultimately required in the whole organisation of care, and in the wider society that supports it. If patient need is to be the unifying factor - then awareness of what this means, will help adaptation. It seems appropriate in this subjective study to repeat a statement of Mrs F (Hospice) as representative of others. As she openly faced dying, and its existential loneliness (Elias, 1985), she was clear that her quality of life needs centred around the expertise that brought freedom from pain, the warm interaction, with members of different disciplines, that soothed distress and enabled her to make best use of that expertise, and (in other statements) the provisions that enabled her to use restored energies to live life as fully as possible:

'The greatest need is love - although medicines do quite a lot - it's attitude isn't it - it's love with which you receive these things'.
BIBLIOGRAPHY


Aitken-Swan J (1959) 'Nursing the late cancer patient at home', Practitioner 183. pp 64 - 69.


Bardelli D and Saracci R (1978) 'Measuring the quality of life in cancer clinical trials: a sample survey of published trials', In Armitage P and


Bates T D (1985a) St Thomas' Hospital Terminal Care Support Team; eighth annual report Available from Sec. Support Care Team. St Thomas' Hospital. London. SE1 7EH.

Bates T D (1985b) 'A clinicians view on terminal care and quality of life' Effective Health Care 2:5.


Bell H K (1985) 'The Spiritual Care Component of Palliative Care' Seminars in Oncology Vol 12, No 4 (December) pp 482 - 485.


Castledine G (1982) 'The way we were.' Nursing Mirror 154 p 39.

Chambers Twentieth Century Dictionary (1973) A.M Macdonald (ed). Chambers


Cobliner W G (1977) 'Psychological factors in gynaecological or breast malignancies' Hospital Physician 10. pp 38 - 40.


Department of Health - Nursing Division (1989) A strategy for Nursing London. HMSO.

DHSS (1972) Care of the Dying Proceedings of a National Symposium. 29 Nov. Reports on Health and Social Subjects No 5. HMSO.


DHSS (1981) Standards of Nursing Care - The Nursing Process - A systematic and Problem Solving Approach to Nursing Care Letter from Chief Nursing Officer CNO(81) 5 CNO(SNC)(81) 2nd June 1.


Engquist C L (1979) 'Can Quality of Life be Evaluated?' Hospitals Nov.16:53 (22) pp 97 - 100.


Gladders P Unpublished Communication.


Goldberg I K (1973) 'Psychopharmacologic and analgesic agents employed in the terminal care of 100 cancer patients' Goldberg, I.K; Malitz, S; Kutscher, A.H (eds) Psychopharmacologic Agents For the Terminally Ill and Bereaved New York. Columbia University Press.


Hanratty J Personal Communication.


Hughes H L (1960) 'Peace at the last: a survey of Terminal Care in the United Kingdom'. A Report to the Calouste Gulbenkian Foundation. United Kingdom and Commonwealth Branch. London


Jermain C (1986) 'To achieve, and then to die' The Times Friday Page. April 18th.


Kathleen W (1979) 'Cancer it feels like this' Nursing Mirror 149. 13 Sep. pp 32 - 33.


Marie Curie Memorial Foundation with the Queen’s Institute of District Nursing (1952) *Report on a National Survey Concerning Patients with Cancer Nursed at Home* April.


Miller J F (1983) Coping with chronic illness: Overcoming powerlessness Philadelphia.: F.A. Davis. in


Parkes C M (1975) 'The emotional impact of cancer of ear, nose and throat on patients and their families' Journal of Laryngology and Otology 89. p1271.


Peplau H (1952) Interpersonal Relations in Nursing New York. Pitman USA.


Pottle A (1990) 'To visit - or not to visit' Nursing Practice 3:2. pp 7 - 11.


Rees D ‘Personal View’ British Medical Journal. 2. p 164.


Saunders C M (1965) 'Watch with me' Nursing Times Nov. 26th.


Shanas E and Binstock R (1976) (eds) Handbook of Aging and the Social Services


Stewart A L (1983) 'Assuring Good Quality of Life Measures in Cancer Clinical Trials' Quality of Life - Methods of Measurement and Related Areas -Proceedings from the 4th Workshop EORTC Study Group on Quality of Life. pp. 1-59.


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Wright S G (1990a) ‘Selling out’ *Nursing Standard* Jan.3. 4:15. p 46.


APPENDIX 1

RESPONDENTS - HOSPICE 'RANDOM' AND HOSPITAL 'CONVENIENCE' SAMPLES

THE HOSPICE

In order to retain the promised confidentiality these details include only an indication of age (although there are some references to exact age which have been left in the quotes as this has been spontaneously offered), and actual or previous occupation when known. Some of the patients had preferred not to give details of occupation feeling that 'retired' or 'housewife' was all that was necessary and hospice staff were particularly keen to respect this choice.

Professional occupations included teaching, nursing, welfare and social work, the Civil Service and various types of administration.

Skilled occupations included that of telephonist, receptionist, secretary, tailor, dress-maker, cabinet maker, butcher, inspector, mechanic, cook, chef, steel erector, bricklayer, salesman and manager of small units such as shops or departments.

Semi-skilled occupations include factory worker, clerical worker, canteen worker, costermonger, heel-coverer, manual worker and seaman.

Admission

Admission to the hospice direct from home sometimes meant admission from the home of a family member.

Hospital Experience

All of the hospice patients had had at least one hospital admission in the course of their illness and some several - for diagnostic purposes and various types of surgery, radiotherapy, chemotherapy and other investigations or treatments.

HOSPICE QUASI-RANDOM SAMPLE n = 52

This sample is identified by alphabetical lettering.

Mrs A 80s Widowed - admitted from home - skilled.
Mrs B 70s Widowed - admitted from hospital - housewife.
Mrs C 60s Married - admitted from hospital - housewife.
Mrs D 50s Married - admitted from hospital - professional.
Mrs E 80s Widowed - admitted from hospital - professional.
Mrs F 70s Widowed - admitted from home - housewife.
Mrs G 70s Married - admitted from home - housewife.
Mrs H 70s Widowed - admitted from home - skilled.
Mrs I 50s Divorced - admitted from home - professional.
Mrs J 50s Married - admitted from home - housewife.
Mrs K 80s Married - admitted from hospital - housewife.
Mrs L 60s Widowed - admitted from home - skilled.
Mrs M 70s Widowed - admitted from home - housewife.
Mrs N 70s Widowed - admitted from home - housewife.
Mrs O 80s Widowed - admitted from home - housewife.
Mrs P 60s Married - admitted from hospital - housewife.
Mrs Q 70s Widowed - admitted from home - semi-skilled.
Mrs R 60s Widowed - admitted from home - semi-skilled.
Mrs S 70s Widowed - admitted from home - semi-skilled.
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Status</th>
<th>Admittance Location</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
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<td>Mrs T</td>
<td>70s</td>
<td>Married</td>
<td>from home</td>
<td>semi-skilled</td>
</tr>
<tr>
<td>Mrs U</td>
<td>70s</td>
<td>Widowed</td>
<td>from home</td>
<td>housewife</td>
</tr>
<tr>
<td>Mrs V</td>
<td>70s</td>
<td>Widowed</td>
<td>from hospital</td>
<td>housewife</td>
</tr>
<tr>
<td>Mrs W</td>
<td>70s</td>
<td>Widowed</td>
<td></td>
<td>housewife</td>
</tr>
<tr>
<td>Mrs X</td>
<td>70s</td>
<td>Widowed</td>
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</tr>
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<td>skilled</td>
</tr>
<tr>
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</tr>
<tr>
<td>Miss C</td>
<td>80s</td>
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<td>skilled</td>
</tr>
<tr>
<td>Miss D</td>
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</tr>
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</tr>
<tr>
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<td>professional</td>
</tr>
<tr>
<td>Mr G</td>
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<td>from home</td>
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</tr>
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<td>Mr H</td>
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<td>Mr I</td>
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HOSPICE CONVENIENCE SAMPLE n = 21

This sample is identified by alphabetical lettering followed by the letter D

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<td>from hospital</td>
<td>skilled</td>
</tr>
<tr>
<td>Mr BD</td>
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<td>Married</td>
<td>from home</td>
<td>semi-skilled</td>
</tr>
<tr>
<td>Mr CD</td>
<td>60s</td>
<td>Married</td>
<td>from home</td>
<td>skilled</td>
</tr>
<tr>
<td>Mr ED</td>
<td>60s</td>
<td>Married</td>
<td>from hospital</td>
<td>skilled</td>
</tr>
<tr>
<td>Mrs FD</td>
<td>40s</td>
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<td>from hospital</td>
<td>housewife</td>
</tr>
<tr>
<td>Mrs GD</td>
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<td>Married</td>
<td>from hospital</td>
<td>professional</td>
</tr>
<tr>
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<tr>
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<td>Mrs KD</td>
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<td>Mrs MD</td>
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HOSPITAL CONVENIENCE SAMPLE n = 22
This sample is identified by alphabetical lettering preceded by the letter P.
General information about these patients was often incomplete because there was no formal access to records as in the hospice; busy staff were asked but some did not feel they had the authority to provide details.

Mrs PA 70s -
Mrs PB 70s
Mrs PC 50s - Married
Mrs PD 40s
Mrs PE 70s - Married
Mrs PF 70s - Widowed
Mrs PG 70s - Widowed
Mrs PH 70s - Widowed
Mrs PI 50s - Widowed
Mrs PJ 80s - Widowed
Mrs PK 80s - Widowed
Mrs PL 40s - Married
Mrs PM 60s
Mrs PN 50s - Married
Mrs PO 70s - Widowed

Mr PA 70s - Married - professional
Mr PB 70s
Mr PC 70s - Married - skilled
Mr PD 60s - Single - professional
Mr PE 40s - Married
Mr PF 40s - Married
Mr PG 70s
APPENDIX 2

INTERVIEW GUIDE

DATE

INTERVIEW NO:

STUDY NO:

NAME

INTERVIEW GUIDE - The order of questions was strictly adhered to.

Introduction - Explanation as to the purpose of the research and invitation to participate in it, with no obligation to do so. Assurance that response would be kept confidential and never related to the patient by name.

1. The main question - 'What is important to you today for your quality of life?

   Probes - At the end of interview if respondent's focus entirely on physical aspects - probe - Anything important to your mind for your quality of life?, or if entirely psycho-social - Anything important to your body for your quality of life? Otherwise only neutral probes were applied e.g please could you enlarge upon this or tell me more.

2. Q.L. Visual Analogue Scale (Hospice sample only)

   FEELINGS ABOUT QUALITY OF LIFE AT PRESENT

   Delighted..............................................................Terrible

3. How comfortable are you?

4. Thanks - assurance of usefulness and confidentiality.
APPENDIX 3

STAFF OPINIONS - RECORDS AND INTERVIEW FOR EACH MEMBER OF THE HOSPICE SAMPLE

This information was kept strictly confidential.

DATE
STUDY NO:

SYMPTOMS ON ADMISSION

PATIENT’S PRESENT CONDITION

Improving
Static
Deteriorating slowly
Deteriorating fast

SYMPTOMS EXPERIENCED - e.g. Pain, Nausea, Vomiting, Anorexia, Constipation, Breathlessness, Paralysis, Insomnia, Difficulty in swallowing.

List VS = Very severe S = Severe M = Mild

FUNCTIONAL ABILITY F = Full nursing help P = Part nursing help
I = Independent Other comments as appropriate

Washing Toilet
Feeding Mobility

SOCIAL RELATIONSHIPS G = good F = Fair P = Poor Other comment

Family
Friends
Staff
STAFF INTERVIEW GUIDE

A senior member of staff who knew the patient was interviewed.

1. What factors seem to you to be important to the patient's quality of life? (Well-being or satisfaction)

2. Are there any other comments that you would like to make that might help in an understanding of this patient's situation?
APPENDIX 4

VISITORS SURVEY

A questionnaire given to professional visitors (mainly nurses) attending St Joseph’s Hospice for an educational session.

This is a small survey to help us to meet the needs of our professional visitors. There is no obligation for you to complete it but we would be grateful for your help. As you will see no name or address is required and anything that you write will not be related to you or to the group of which you are a part.

SURVEY

1. Our visitors have many different areas of interest; some are outlined below. Please tick the area(s) that you are interested in, or if ‘none’ or ‘don’t know’ is appropriate please tick one of these categories.

   Bereavement
   Home Care
   Relating/communicating with dying patient
   Symptom control
   Physical care of dying patient
   The emotional needs of dying patients
   None
   Don’t know

2. This is a similar list. Please tick those areas where you feel some exploration in depth would really help you in your work, or tick ‘none’ or ‘don’t know’.

   Symptom control
   Relating/communicating with dying patients
   Bereavement
   Home Care
   Physical care of dying patients
   The emotional needs of dying patients
   None
   Don’t know
APPENDIX 5.

MEDICAL STUDENT RESEARCH

As part of the background to this study a small pilot project was undertaken in 1985 with seven medical students gaining 'elective' experience at the hospice. The purpose was to gain some greater insight into the differences between the hospice and the modern teaching hospital, which might indicate some of the problems likely to be met in bringing hospice type care to hospitals. This small sample consisted of four students from Britain and three from two different EEC countries. All had arrived singly, were nearly at the end of their medical training, and had been at the hospice for some time.

STUDENT RESPONDENTS
Student A from country X
Student B from country X
Student C from Britain.
Student D from Britain
Student E from country Y.
Student F from Britain.
Student G from Britain.

Each student was asked, 'I (the researcher) have been here (the hospice) for four years now, so perhaps I am beginning to forget what it is like in hospital - do you find a difference here? The response was spontaneous and not prompted, except with neutral probes to try to amplify the statements. All of the students gave their permission for their response to be used in research and teaching and were assured that the data would not be related to them personally.
This project was undertaken with a small convenience sample of seven terminally ill patients at St Joseph's Hospice. They are identified by alphabetical lettering followed by the letter X. All patients who were approached responded positively to the invitation to partake in the research.

Mrs AX - 60s
Mrs CX - 50s
Mrs EX - 60s
Mrs FX - 70s
Mr BX - 60s
Mr DX - 60s
Mr GX - 60s

Introduction
Sometimes patients have found it difficult in hospitals to talk to staff - to get through to them - to share thoughts and feelings. Doctors and nurses are trying to learn how to improve this situation. In order to help, please could I ask you a few questions? There are no right or wrong answers. What you say would be kept confidential and not related to you in any way. You do not have any obligation to take part in this research, and whether you do or not, will not affect your treatment in any way.

1. ABOUT DIFFERENT SITUATIONS THAT CAN ARISE

Who would be the best person to talk to if a patient had:

a. A pain?

b. Was worried about family business or things outside?

c. Wanted to discuss his/her illness?

d. Felt bored or lonely?

e. Was dissatisfied with the food?

2. ABOUT PEOPLE BEING APPROACHABLE

a. What kind of doctor is not very approachable - you feel puts someone off talking to him or her?

b. What kind of nurse is not very approachable - you feel puts someone off talking to him or her?
c. What kind of doctor do you feel is approachable - whom people would feel encouraged to talk to?

d. What kind of nurse do you feel is approachable - whom people would feel encouraged to talk to?

3. IS THERE ANY EXPERIENCE RELATING TO COMMUNICATION PROBLEMS THAT YOU WOULD LIKE TO SHARE?  
(Only neutral probes were used)