

**STRESS AND DEATH ATTITUDES IN NURSES**

**Thesis submitted for the degree of**

**Doctor of Philosophy**

**at the University of Leicester**

**by**

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## STRESS AND DEATH ATTITUDES IN NURSES, S A McNeely

### ABSTRACT

Both qualitative and quantitative methods are used to investigate stress and death attitudes in nurses (n=308) from three clinical areas (palliative, psychiatric and general nursing). The work investigates: the experience of stress (reported sources and levels, coping strategies); fear of death (based on Howells et al., 1986, with nurses' reported fears compared with those reported by a general population sample); coping with death and caring for dying patients (nurses' perceived ability to cope and elements of the experience of patient death which contribute to stress); and perceived effects of working with the dying. Results show differences on fear of death across nursing groups and between nurses and the general population sample suggesting that nursing work does affect levels of fear of death in some respects. Patient death ranks seventh on a list of 24 sources of stress and appears to be perceived by nurses as a unique stressor. Nurses report a range of coping strategies, most important of which is the use of social support, but often regard their coping strategies as less than effective. Evidence indicates that many nurses perceive their training to have been inadequate to deal with some aspects of caring for the dying and general nurses report less confidence in their ability to cope with death and dying issues than the other groups. Qualitative accounts emphasise nurses' aims to provide 'good death' for their patients and suggest that failure in that aim increases the nurses' stress and that working with the dying can have a major impact on nurses' lives and relationships with others. It is concluded that some difficult aspects of the experience may not be amenable to change, making adequate and effective coping strategies an important goal for nurses engaged in this work and suggesting implications for training and organisational provision of social support.

## **CHAPTER ONE**

### **Introduction and Literature Review**

#### **1.1 - Introduction**

Patient death is, for most nurses, an event encountered at some time in their career. It is, perhaps, during the final part of a patient's life that a nurse is called upon to give most, in terms of professional medical care, but especially in terms of psychological care, human kindness and sympathy, emotional sharing or what James (1989) and Smith (1992) have called emotional labour. It is not surprising that dealing with death and dying is reported by many researchers (Vachon, 1987; Gray-Toft and Anderson, 1986-1987; Tyler et al., 1991; Snape and Cavanagh, 1993) as one of the important sources of occupational stress in nursing.

The main focus of this study is the stress which nurses from three clinical areas (palliative, psychiatric and general nursing) associate with patient death. The work is guided by the transactional perspective on stress, as proposed by Lazarus and Folkman (1984), which is widely accepted and used in the literature. The study investigates the relative importance of patient death among other sources of stress, elements of the experience of patient death which affect nurses' appraisals of stress, reported coping strategies and effects of working with the dying. It also assesses nurses' perceived ability to cope with death and dying, levels of fear of death (which may influence coping), burnout and psychological well-being and examines whether nurses' appraisals and perceptions reflect their organisational context or clinical area.

Initially, the researcher's interest in this topic arose from personal experience, watching a friend travel through the final stages of cancer, cared for at home, then in hospice, and then finally, as she had wished, returning home to die. One striking feature of this experience was the unflinching care delivered by nurses in both settings, to a patient whose final weeks of life presented many challenges for her carers.

The experience highlighted, for the researcher, how the nurse is in the front line of caring, and how that front line work can be 'dirty work' in many ways, both practical and emotional. While the doctor is considered to be the expert in treatment during the earlier stages of the illness, most often, s/he has the opportunity to walk away and leave the final difficult stages to someone else. That someone else is usually the nurse. This and other experiences also confirmed, for the researcher, that death and dying remain difficult subjects which, too often, are only confronted or discussed when one is faced with the reality of personal loss. Further, it appeared that among the public and perhaps among medical professionals in management positions, death and dying are still too often accepted as 'just part of being a nurse' without due regard to the effects and consequences of doing that work.

A small (n=27) undergraduate study of how nurses coped with death and dying (McNeely, 1993) revealed that some nurses felt insufficiently trained to cope with several aspects of nursing the dying patient and dealing with relatives. This raised further questions about nurses' perceptions of their competency to deal with death and dying, about their fears about death and dying, about their methods of coping, about the consequences, for the nurse, of doing this work and about whether or how the nursing experience of patient death could be modified to provide good care for the patient, with fewer adverse effects for the nurse. An investigation of the literature revealed that some of these questions had not been fully answered. The important issues relating to death attitudes have not been addressed, and this study aims to explore some of those issues.

The literature review will take the following course. As patient death has been regarded as a major source of stress for nurses (Gray-Toft and Anderson, 1981b; Vachon, 1987; Cooper and Mitchell, 1990; Snape and Cavanagh, 1993), an understanding of the definition of stress which is applied in this study is required. Current research in the field of psychological stress generally favours the transactional perspective which accounts for the individual and his/her environment and the relationship between the two. Therefore, the transactional perspective of stress and appraisal as described by Lazarus and Folkman (1984) will be summarised and used as a guiding framework in this study. Reported sources of stress in nursing, with an emphasis on the experience of nursing dying patients, will be explored.

The consequences of long-term chronic stress are now widely acknowledged to include both physical and psychological effects (Cox, 1978; Maslach and Jackson, 1986; Sutherland and Cooper, 1990). Nursing has also been identified as one of the human service professions in which members are vulnerable to 'burnout', defined and discussed below in section 1.4.3, which is a possible result of long-term chronic stress (Cherniss, 1980; Maslach and Jackson, 1986). The literature review will, therefore, discuss the possible consequences of nurses' stress, for the nurse, for the patient and for the organisation.

This will be followed by a discussion of nurses' coping strategies, and some factors which may influence the coping process, including some attitudes to death and different organisational settings. A critique of the literature will be followed by a summary of the questions which have emerged from the literature and the hypotheses and research questions which are being addressed in this work.

## **1.2 - Stress**

This section will briefly outline the historical changes of perspective within stress research. This will be followed by a review and evaluation of the transactional perspective of stress as described by Lazarus and Folkman (1984), and a discussion of how the model proposed by Lazarus and Folkman is applied to nursing groups in this project

### **1.2.1 - Historical Perspectives**

During the last fifty years the study of stress has moved through three perspectives wherein stress has been viewed as a response of the body to some stimulus (Selye, 1950); as a stimulus, generally of an environmental nature, which creates an effect on the individual or group (Dohrenwend and Dohrenwend, 1974); and more recently, as a complex transaction between an individual and the environment (Cox and Mackay, 1976, Lazarus and Folkman, 1984).

Current attention tends to focus on interactional or transactional models of stress (Cox and Mackay, 1976, Lazarus and Folkman, 1984) since psychologists have accepted the importance of both person and environment in most aspects of human behaviour. These

models focus on a process wherein a person perceives some demand, makes some decision about how to meet the demand and responds in some way to that perceived demand (the response may be to ignore the demand). Essential to these approaches is the idea that the individual makes a cognitive assessment of the situation and reacts to whatever demands are perceived, on the basis of that assessment. As in the model proposed by Cox and Mackay (1976), stress arises when there is an imbalance between perceived demand and perceived ability to cope with the demand. They emphasise that "stress is an individual perceptual phenomenon rooted in psychological processes" (Cox, 1978, p18).

The importance of the cognitive assessment or 'appraisal' part of this phenomenon cannot be overstated in transactional models of stress. Lazarus (1966) asserted that there are three kinds of appraisal in a potentially stressful situation. Primary appraisal involves the problem or the demand and interpreting the significance of the demand. Secondary appraisal focuses on possible responses to the demand (coping strategies). Tertiary appraisal is concerned with assessing the possible consequences of whatever response might be offered. Further, Lazarus and Folkman (1984) explain that reappraisal happens after some additional information or feedback is received and the individual needs to take a second look at whether the demand is still significant and/or how to cope with the demand.

Since the experience of patient death is being investigated in terms of its subjective importance as a source of stress and is also being analysed to determine elements which might be modified, it is essential to consider, in more detail, the definition and perspective of stress which is used as a conceptual guide or framework in this study. It is the work of Lazarus and Folkman (1984), in particular, their perception of stress and appraisal as a transactional process, which is used as a conceptual framework throughout this study and which is summarised below.

### 1.2.2 - A Transactional Model of Stress (Lazarus and Folkman, 1984)

If the interaction between a person and their environment is to be fully considered, then three elements must be accounted for, ie the characteristics of the individual, the nature of their environment and finally the relationship between the two. It is this concept which is the basis of the definition of psychological stress given by Lazarus and Folkman (1984): **"Psychological stress, therefore, is a relationship between the person and the**



**environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being."**(p 21)

The use of the term '**relationship**' implies a dynamic situation involving feedback and informational exchange in some form between the person and the environment. The word '**appraised**' is crucial to the definition because, according to Lazarus and Folkman, in order for a situation to be judged to be stressful, the person must make a cognitive evaluation of the situation to that effect. The person will decide that the situation is stressful if s/he appraises the situation as "taxing or exceeding his or her resources" AND "endangering his or her well-being".

**Primary appraisal** may result in three kinds of decisions about a situation. An 'irrelevant' situation will have no effect on the well-being of an individual. It will incur no cost and no reward for the individual in terms of beliefs or commitments. 'Benign-positive' situations will be those which, for this individual, carry some expectation of maintaining or enhancing personal well-being. These may also involve some feelings of anxiety or apprehension about the permanence of this desirable situation. Finally, Lazarus and Folkman identify the three kinds of appraisals which conclude that there is 'stress' in this situation.

'**Stress**' appraisals will result from situations of "**harm/loss**" where the person has already suffered damage or loss. Examples would be illness, injury or bereavement and the most serious or harmful of these situations will be where the individual has lost some major commitment. The other two kinds of stress appraisals, "**threat**" and "**challenge**", demand that the individual makes some effort to ward off impending harm. **Threat** refers to anticipated or potential harm or loss and may occur alongside harm/loss appraisals in, for example, the case of serious illness when the prognosis is uncertain. **Challenge** differs from threat in that it recognises the potential within a situation for growth or gain. There may be emotions of excitement and pleasurable anticipation rather than the fear, anxiety and anger which may accompany a threat appraisal. Threat and challenge appraisals may result simultaneously from the same encounter with the environment. Lazarus and Folkman (1984) have also emphasised that a situation which is appraised as threatening may come to be viewed as challenging (or vice versa) because of some change in the situation or because the person changes their perception of the situation, possibly by learning new coping skills.

It is **secondary appraisal** which will indicate whether the individual feels s/he has the resources to cope with the situation when faced with threat. It lies at the heart of whether the outcome of this stressful situation will be favourable or unfavourable. Secondary appraisal is seen as a "complex evaluative process" which involves weighing up the options which might be used to cope and the likely success or failure of those options. The success of this strategy will depend on the availability (perceived and actual) of coping resources, on the correct choice of strategy and/or the person's ability to employ the strategy effectively, taking into consideration all demands and constraints of the particular context.

There are two important points about this process of appraisal which should be noted here. The process may occur, according to Lazarus and Folkman (1984), without the individual being consciously aware of the process or of the factors which influence their decisions. The second point underlines the individuality of the process which is influenced by a range of factors, both subjective and objective.

Subjective or personal factors include 'commitments' or valued goals and 'beliefs' which shape an individual's concept of life. In Lazarus and Folkman's terms, the relationship between individual patterns of commitments and beliefs and available resources to protect those commitments and beliefs plays a vital role in determining how an individual reacts to a perceived threat. Objective or situational factors include the amount of information about the event which is available to the person, and the timing and duration of the event which affect the person's understanding of the event and their ability to summon coping resources.

To conclude the review of the model of the stress process proposed by Lazarus and Folkman (1984), two vital points need to be reiterated. This model is a transactional one which emphasises the constant interplay, the relationship, between person and environment. In this model it is the individual **appraisal** of situations or transactions which is critical in determining whether that transaction is stressful. It is important to remember that personal factors never operate independently but always operate interactively with situational factors to influence that process of appraisal. Secondly, Lazarus and Folkman (1984) have made the point that most factors, whether they are personal or situational

factors, have potential for both negative and positive influences on the amount of threat perceived by an individual. A strong commitment to some aim or ideal may initially increase perceived threat because there is much at stake but may alternatively reduce the perceived threat because that commitment pushes the person to look for, acknowledge and implement all possible coping strategies.

It is important to emphasise the complexity and the individuality of the appraisal process and to note that for any individual many factors contribute to the result. Further, the commitments and beliefs held by an individual will have been shaped by past experience and may change over the life-span of the individual. Lazarus and Folkman (1984) identified achievement motivation, problem solving skills, social skills and social support as additional person factors which will affect cognitive appraisal and vulnerability to stress. Cassidy (1994) has added 'attributional style' and 'hopelessness' to this list because of their relationship to cognitive appraisal, insofar as they reflect thinking processes. Some attempts have also been made to determine the role of personality characteristics such as extraversion/introversion and Type 'A' personality although there is still controversy about the actual structure of personality, the stability of 'personality traits' and the validity of such a construct as Type 'A' personality (Sutherland and Cooper, 1990). Undoubtedly, future research may highlight further additions to the list of factors which influence the appraisal process.

### 1.2.3 - Evaluation of the Lazarus and Folkman (1984) Model of Stress

Although the theory, as explained by Lazarus and Folkman (1984), presents a detailed approach to understanding how the stress process works, there are grounds for criticism. While the complexity of the theory provides potential for a thorough understanding of the transactional approach to stress, it makes the model extremely difficult to test. Any attempt to design an experimental test of the model would leave the researcher with the impossible task of addressing infinite variation in the personal factors (beliefs, commitments, perceptions) of subjects. Consequently, there is likely to be infinite variation in outcome of any tests and it is impossible to design controls for these often unknown factors which may affect subjects' responses. This is one reason why research has tended to focus on the attempt to find and acknowledge those factors which may influence the stress process (sources of stress and mediators in the appraisal process) and to determine

the role of the stress process in terms of human health (links between stress and health, well-being and specific behaviours, most notably researched in the workplace).

It is the same complexity of this model which makes it difficult to apply to a workplace problem in a way which will locate specific sources of stress and provide corrective solutions. The model suggests that, to reduce stress, it should be possible to change either the environment (demands on the individual) or the individual (their perception of the situation in terms of demands and resources to meet the demands). However, in the interaction between individual and environment, it is difficult to determine the importance of each of the many influential factors. Consequently, moderation of any of those factors in the hope of correcting a specific problem, thereby reducing the amount of stress, must be, to some extent, a 'trial and error' procedure. Further, the emphasis on individual appraisal in this model of the stress process places some limitations on its usefulness in finding workplace solutions which must be beneficial to groups rather than individuals.

Briner (1993, 1994) has been very critical of stress theory in general and claims that, because the existing theories are contradictory in approach, the theories have limited usefulness. He apparently fails to see the work of Lazarus and Folkman (1984) as an advance on previous approaches. Briner's (1993) criticisms are largely based on the application of stress theory to occupational settings, where he claims there is a lack of empirical support for conclusions which have been drawn about the relationships among occupational stress, well-being and a range of workplace behaviours such as absenteeism. Further, he takes issue with some stress research methodologies where, for example, causality is attributed on the basis of correlational statistics.

In more general terms, however, Briner (1993, 1994) has criticised the basic concept of stress, claiming that it fails to 'explain' very much. He acknowledges Lazarus and Folkman (1984) in their contention that the term stress should be considered, not as a variable, but as a "rubric consisting of many variables and processes" (p 12). However, he cites the misuse and abuse of the term 'stress' as reason for a weakness in theory which he claims is built on an unclear understanding of the phenomena contained within Lazarus and Folkman's 'rubric'. His suggestion is that the concept of stress should be abandoned and research should aim to be more specific about the phenomena under study. He claims that labelling a person's affective state as 'stress' or stressed is unhelpful and suggests that

more specific labelling of emotions such as anxiety or depression would be more accurate. This would seem to be a more accurate labelling of the effects of stress. Indeed, Lazarus (1990), in his recommendation that research should move towards measurement of emotion rather than measurement of stress, refers to 'stress-induced emotions' (p12) and proposes that a more detailed understanding of the emotions resulting from an appraisal of stress would be more informative regarding how an individual is relating to the environment and coping with demands. Briner acknowledges that there is a relationship between human experience and well-being but claims that stress theories fail to address the complexity of those relationships and so the empirical work based on present theory will be inadequate to uncover those relationships.

Briner's comments are a useful spur to theoretical debate and renewed thinking about this complex area of psychology. There is a need for improvement in operationalization of theory and clarification of terminology within stress research. However, to recommend the abandonment of the entire concept of stress, a concept which has been developed over decades, without proposing some new and more useful concept as a replacement, is, arguably, neither helpful nor constructive in terms of building better theory.

The application of transactional or interactional models of stress to occupational settings has also been criticised by Handy (1986). She contends that there is a need, within the conceptual models of occupational stress, for greater acknowledgement of the relationships between "social structures, actions and private meanings" (p 206). She suggests that individuals may not recognise or understand the role played by organisational structures and powers in the development of stressful situations, and that power, especially the imbalance of power between organisation and employee, has not been adequately considered in stress research. However, Lazarus and Folkman (1984) have considered control and its importance in dealing with potentially stressful situations and there is an obvious relationship between control and power. Further, they have considered the role of context in the stress process, elaborated through their discussion of the situational or environmental elements which affect appraisal. It may be true that individuals do not always appraise correctly, may fail to recognise the real source of threat, and, as a result, may fail to choose or apply an effective coping strategy, at least in the first analysis. This does not necessarily represent a failure in the theoretical concept, but underlines the importance of the appraisal process and the complexity and individuality of the whole

stress process. It is probably true that if, as Llewelyn and Payne (1995) recommend, nurses were better informed about organisational structures and power relationships, this would improve their ability to recognise and cope with related problems. It would help to change the balance of power within the organisations, as Llewelyn and Payne stated, thereby increasing a sense of control and potentially reducing related stress.

Llewelyn and Payne (1995) also propose that some systems may only remain intact at the cost of stress to those individuals who work within them and that both the system and the individual may resist any attempt to confront the issues and make changes which would reduce stress. In the Lazarus and Folkman (1984) theory, this might be explained by the important role played by commitments. They acknowledge that where there is great commitment to something, there is also a greater potential for threat because the individual has more to lose. In nursing, for example, a nurse may have such a strong commitment to caring, and/or to the institution in which s/he works, that s/he is prepared to accept high levels of stress in order to maintain certain standards of care and to avoid any risk to certain aspects of the system. In theoretical terms, this individual may either suffer negative effects of stress because of a resistance to change in situational factors OR the individual may change his/her cognitions about those situational factors to a way of thinking which reduces the harmful effects (a coping strategy) OR may change the situational factors by leaving the situation (a coping strategy). There may be nurses who decide that the level of stress is unacceptable, that there is little that can be done to alleviate the situation and that their only recourse is to leave that job or even the profession. An application of the same transactional model of stress would explain this as the individual coping with a threat by changing the situational factors by leaving the situation.

#### 1.2.4. - Application of the Theory in This Study

This is a study of nurses which aims to understand the psychological processes involved in caring for the dying, and the relationship between patient death and stress in nursing. Notwithstanding the difficulties mentioned above, the theory or perception of stress and appraisal proposed by Lazarus and Folkman (1984) may be helpful in explaining some group differences. As individuals meeting the ordinary demands of daily life, nurses' subjective commitments or beliefs may not differ substantially from those held by the

general population. However, in some circumstances, such as dealing with a dying person, there are certain commitments and beliefs which are inherent in, and specific to, being a nurse. For example, a nurse has made a professional commitment to care for people and psychologically, if not practically, the extent of that commitment may include making the person well again. Cure is generally the main aim of all medical personnel when a patient enters hospital and even though treatment decisions may largely be the responsibility of the doctor, the nurse may be responsible for administering drugs or treatments. Along with this large professional commitment, the nurse will hold certain beliefs about what is expected of her/him by the patient or by the doctors, in terms of behaviour, levels of skill, and response to different events or situations (Melia, 1987; Katz, 1996). S/he may also hold some beliefs about what the medical profession should be able to do or is expected to do for the patient or about the efficacy of treatments. This means that as a group, nurses may share certain factors which affect their appraisal of dealing with a dying person.

Similarly, there may be some shared commitments and beliefs which differ among groups of nurses working in different avenues of the profession. Experience gained from life, from work and education and from training which is aimed at specific kinds of nursing care, will, according to Lazarus and Folkman (1984), have an influence on commitments and beliefs held by different groups of nurses. Nurses who have been trained for and work in psychiatric care will have a major commitment to mental health while not ignoring physical health, but, in a coronary unit, the major commitment may be to improving physical health, while not ignoring mental health. Palliative care nurses working with the dying are committed to symptom control and the best care possible leading to a good death, while in more general nursing units, the major aim is curative.

The importance, in the stress process, of these contextually shared values and goals is recognized by McNamara et al. (1995) in their discussion of stress and coping among Australian hospice nurses (n=22). Their study shows how, for those hospice nurses, stress arose out of their commitment to the hospice philosophies and ideals, especially pertaining to the good death. It was more difficult for nurses to deal with a patient whose wishes did not allow nursing care to fit into the good death model. These differences may extend beyond the subjective commitments and goals to objective differences arising from the organisational settings (hospice versus hospital wards) and support systems available within the structure of organisations. According to the model of stress as explained by

Lazarus and Folkman (1984), these different commitments and beliefs, along with situational differences in the workplace, may help to explain differences among nursing groups in appraisals of the relative importance of different sources of stress.

### **1.3 - Stress in Nursing**

In Section 1.3, the literature on occupational stress in nursing will be reviewed. Particular attention will be given to the experience of patient death as a source of stress. The literature on the 'good death' is reviewed and evaluated, followed by a short discussion of the limitations of death education.

#### **1.3.1 - Sources of Occupational Stress**

Increasingly, workplace changes, such as increased technology and changes in management structures, have altered the occupation of nursing, creating new challenges and demands for employers and employees. Furthermore, the very nature of nursing work requires that individuals are regularly called upon to deal with sickness, trauma, tragedy and death, situations which are accompanied by great potential for stress. Even the more mundane aspects of nursing, such as making beds, changing dressings, and completing the paperwork are often physically taxing, unpleasant and tedious.

In nursing, the link between occupational stress and anxiety, depression and absenteeism was recognised more than a decade ago (Hingley and Cooper, 1986). As research has increased, there have been many studies, some of which are reviewed below, which have listed sources of stress and reported on coping strategies and their effectiveness, seeking to make recommendations for changes which would reduce the stressful nature of some aspects of nursing (Tyler et al., 1991; Schaefer and Peterson, 1992; Snape and Cavanagh, 1993; Sullivan, 1993 and Leary et al., 1995).

Within the extensive research literature on the subject of stress in nursing, some studies focus on specific areas within the profession and some make comparisons between clinical areas. For example, Crickmore (1987) reviewed a range of studies which examined stress in intensive care units and concluded that nurse/patient relationships and exposure to death and dying were major stressors for nurses in intensive care. Snape and Cavanagh (1993)



studied a small sample (n=31) of neurosurgical nurses and reported that 'being exposed to life and death situations' and 'being short of essential resources' were the stressors which had greatest effect on nurses' work. Tyler and Cushway (1992) studied stress, coping and mental well-being in 72 nurses from one hospital, using the General Health Questionnaire (GHQ-28). They concluded that stress-related disorders in nurses could be alleviated if excessive workloads could be reduced and appropriate coping strategies implemented by nurses. Sullivan (1993) used Lazarus' and Folkman's (1984) transactional theory of stress as the conceptual basis for his exploratory study of stress in psychiatric nursing and reported that, while psychiatric nurses are exposed to stressors which are common to other units (workload, staffing problems and administrative chores), they also encounter stressors which reflect the particular client group with which they work (violent incidents and the need for constant observation).

Among the comparative studies, Tyler and Ellison (1994) investigated stress in 60 nurses from four high-dependency areas of nursing (theatres, liver / renal, haematology / oncology and elective surgery), reporting that the amount of stress (General Health Questionnaire) was similar across the four clinical areas but perceived sources of stress differed. In particular, theatre nurses reported less stress associated with death and dying. A comparison of stress in nurses in the public and private sectors was reported in 1991 by Tyler et al.. The 28-item General Health Questionnaire was used in that study with the finding that levels of well-being were similar across the two groups. Death and dying and workload emerged as the most frequent sources of stress but there were some differences; workload was a more frequent source of stress for NHS nurses and public sector nurses reported more conflict with doctors and greater uncertainty about treatments. Foxall et al. (1990) compared frequency of stressors and sources of job stress perceived by nurses in some American intensive care, hospice and medical-surgical units. They report many similarities in sources of stress across the four groups but death and dying situations were reported as more stressful by those nurses who were more likely to encounter such events on a daily basis.

There is a considerable amount of work from abroad which includes the earlier work of Gray-Toft and Anderson (1981a, 1981b, 1986-1987), from the United States, developing the Nursing Stress Scale (Gray-Toft and Anderson, 1981a). Their sample of 122 nurses was drawn from five units of a private, general hospital. Findings indicated that workload,

feeling inadequately prepared to cope with emotional demands of patients and families and death and dying were regarded as the major sources of stress. Gray-Toft and Anderson (1981b) also reported that significant effects on job satisfaction and turnover were attributable to stress. Gray-Toft and Anderson (1986-87) investigated sources of stress among nursing staff (n=17) working in a hospice unit within a larger hospital. Qualitative methods used material from interviews, observations, incident reports written by nurses and support group discussions. Emotional demands of the work and the continual and exclusive involvement with dying patients were major sources of stress for this sample but nurses also reported their work to be personally and professionally satisfying. Vachon (1987) from Canada has provided a comprehensive study of stress in caregivers, including nurses, who work with the dying (see some findings below). Cross and Fallon (1985), in an Australian study, examined sources of stress in critical care, surgical, obstetric and medical nursing specialties and highlighted the need to respect the different needs of different clinical areas of nursing. It can be seen that both qualitative and quantitative methods have produced ample evidence of stress in nursing. From the literature, several conclusions can be drawn.

The first point is that nursing is a stressful occupation for many if not most people who work in the profession. The overwhelming body of literature reports that nurses find many different elements of their work stressful. Generally, the degree of reported stress experienced among different groups of nurses is similar (Foxall et al., 1990; Tyler et al., 1991; Tyler and Ellison, 1994).

The second point is that there is considerable evidence to suggest that, while some events or situations are stressful for most nurses, the importance of a particular source of stress may vary with the different nursing roles ( see above and Tyler and Cushway, 1992; Foxall et al., 1990; Cross and Fallon, 1985). This is not surprising when one considers the different kinds of work done by, for example, a psychiatric nurse and someone working in a medical-surgical ward. Coping with a violent patient may be a frequent and stressful event for the psychiatric nurse, but the medical-surgical nurse may never have to contend with a violent patient and may not report that as a source of work-related stress.

One may conclude from the literature that many of the stressors within the profession of nursing cannot be removed. The variety and complexity of human interaction makes it

likely that, as long as people work together, there will be difficulties and stress caused by interpersonal relationships, between peer groups, between levels of staff and between departments. Patient death and distraught relatives will always be a feature of the nursing role. Thus the potential for related stress will always be present.

Not surprisingly, the research reveals a long list of sources of stress for nurses. Death and dying, workload, insufficient support from the organisation, dealing with relatives, role confidence and competence, home/work conflicts, shortage of resources, interpersonal relationships, difficult patients, and others have been identified (Gray-Toft and Anderson, 1981b; Dewe, 1987; Cooper and Mitchell, 1990; Sullivan, 1993; Snape and Cavanagh, 1993). Heavy workloads and inadequate staffing have frequently been reported as sources of much stress and, according to Tyler and Cushway (1992), this problem is increasing as a result of recent organizational changes.

Although Sutherland and Cooper (1990) acknowledge the link between stress and physical, psychological and behavioural characteristics, they also suggest that there may be unnecessary concern about the harmful effects of stress on the health and welfare of nurses. Sutherland and Cooper have criticised the research of stress in nursing because of reliance on self-report measures and conclude that there is a need for combined objective (physiological) and subjective measures to be used. The problems associated with obtaining objective measures from large samples of nurses (or most other populations) are obvious. Constraints of time, funding and permission for access to nurses for such research are no doubt among the reasons why more objective research has not been done. Still further, if large numbers of nurses state that there are many important stressors in their work, it does not necessarily follow that there will be obvious and/or objectively measurable symptoms of negative effects in those same numbers. Coping is about learning to deal with stressful situations in a way which will alleviate those negative effects (Pearlin and Schooler, 1978) and, while nurses may work in very stressful roles, they may also have strong coping mechanisms in place. Indeed, the weakness of the self-report measure, whether qualitative or quantitative, may be more significant in measuring the negative effects of stress than in determining sources of stress. While nurses may speak frankly about what they perceive to be the cause of their stress, many nurses may well be reluctant to disclose, even anonymously, substance abuse, insomnia, visits to their doctors or other symptoms which could be construed as negative effects of stress and which may present an

uncomplimentary picture of an employee. It is highly possible that the true incidence of the negative effects of stress is underestimated, rather than overestimated, by self-report methods of research.

### 1.3.2 - Patient Death as a Source of Stress

Whether by using observation and interviews (Gray-Toft and Anderson, 1986-1987), by self-report questionnaire (Cooper and Mitchell, 1990; Tyler et al., 1991) or by log-books (Snape and Cavanagh, 1993), the evidence gathered clearly indicates that death and dying and relationships with patients and their families rank high, alongside workload, in terms of stress-causation. Patient death is a more frequent occurrence in some areas of nursing than in others, and in some units may even be a rare event. However, the possibility for such an event is almost omnipresent and given the position of intimacy, trust and responsibility for care which the nurse accepts, whenever there is a patient death, there is great potential for stress and emotional repercussions for the nurse.

For most nurses who work in general hospital settings and some psychiatric units, patient death may be an occasional event. For those who work in palliative care units and hospice settings, patient death may occur very frequently, and the nurse knows that death is a relatively imminent event for all patients who are admitted. Patients in those units are very ill and usually require a great deal of nursing care of both a physical and a psychological nature. Field (1989) reported that nurses in his sample appeared to find no real difference in the amount of stress experienced, whether nursing dying patients or those who were recovering. However, Katz (1996) has reported that nurses view dying patients as “the ultimate challenge to providing total care” (p129).

Inherent throughout the occupation of nursing, and particularly in terminal/palliative care nursing, is the establishment of a relationship with a patient. The very nature of the nursing role means that, nurses are more likely than other health professionals to form close personal relationships with their clients. Although nurses are often cautioned not to become emotionally involved with patients, the nursing process and holistic care make it difficult to avoid such involvement (Field, 1989). As with any relationship, there is an investment and inevitably a sense of loss when it ends with death. The nurse becomes the bereaved. The death of patients does not fit comfortably with common perceptions of the

nursing role as that of the strong one who is 'in control' (Fisher, 1991), saving lives and protecting people from pain and distress. When patient death does occur, the nurse may have feelings of failure (Scully, 1980) and helplessness, questioning the adequacy of care which has been given (Fisher, 1991).

When caring for the terminally ill and bereaved families, nurses may also feel conflict between the need to be warm and compassionate and the need to maintain the professional approach (Crickmore, 1987; Smith, 1992). In the past, maintaining this professional manner may have included keeping information from the patient so that the process of illness and dying remained more emotionally controlled (James, 1993). There is now, however, a greater demand from patients to be informed (Llewelyn and Payne, 1995). As a result, for cancer or AIDS patients for example, there is often a greater awareness of prognosis. This places a heavy burden on nurses who, still charged with the need for a professional manner, must confront and discuss emotional issues of the greatest impact. Like Glaser and Strauss (1968), Field (1989) concluded that trained nurses found it easier to cope with dying patients who were aware of their impending death. They preferred an atmosphere of openness between patient and nurse although they sometimes found it difficult to cope with patients' questions and requests for information. These feelings of conflict, responsibility and the need to appear professionally controlled may be emphasised after the death of the patient when the nurse needs to grieve, for "How a person mourns is determined, to some extent, by the way he is expected to mourn" (Parkes, 1985, p 12). The perceived demands of the professional role may result in some nurses feeling unable to acknowledge their personal emotions or to grieve in a healthy open manner.

Raphael (1980) has suggested that working with the terminally ill and the bereaved causes carers to empathise and identify strongly with their patients because of the universality of the loss experience. This makes it difficult for palliative nurses not to become over-identified with their patients (Fisher, 1991). Indeed, Adams et al. (1991) have stated that one of the characteristics of 'Accumulated Loss Phenomenon' (discussed below), which is said to be suffered by hospice nurses, is the presence of "thoughts or anxieties about personal or imagined scenarios of illness, disability and death" (p30).

A range of psychological and behavioural manifestations of occupational stress in caring for the dying was identified by Vachon (1987). Depression, grief, guilt, anger, irritability,

frustration, helplessness, anxiety, indecision and burnout were all cited as feelings experienced by a range of workers who included nurses, doctors and other caregivers from a range of specialisms and care-unit types. As well as a variety of stress-related physical complaints (such as insomnia and gastro-intestinal complaints), Vachon found that common behavioural manifestations of stress included conflict with other staff, conflict with family and making mistakes.

Although there are many similarities of experience among different groups of those who care for the dying, there are differences too. One of the main features of the nursing role is, perhaps, the duration of the relationship between nurse and patient. Generally the amount of time spent by a nurse with a given patient is much greater than that spent by the doctor, especially where nursing units operate the primary nursing approach wherein nurses take more complete responsibility for a patient's care, rather than doing one task for every patient. Frequently, too, the caring role of the nurse involves greater levels of intimacy, both physical and emotional, not only with the patient but often with the relatives as well. It is likely that this increased time spent with patients would result in a more intense emotional involvement between nurse and patient (Field, 1989; Llewelyn and Payne, 1995), and a stronger relationship than would normally be found between the patient and other members of the professional care team. This, in turn, is likely to increase the amount of grief felt by the nurse when the patient dies (Parkes, 1986,1996).

It has also been suggested that nursing the dying can have positive effects on nurses and can be a source of personal growth and job satisfaction (Field, 1989; Fisher, 1991). On the basis of his study of nurses, Field (1989) suggests that this may be increased where nursing is organized so that each nurse has responsibility for total care of a patient, thereby increasing the time of contact and emotional involvement.

It is hardly surprising that nurses often report patient death as a stressful experience, or a stressor, in their workplace. It is likely that the ending of any life, in any circumstance, must carry with it some sadness and a measure of emotion but a more careful analysis of the experience is necessary if ways are to be found to reduce the negative effects on the nurse. If nurses are experiencing high levels of stress in dealing with dying patients, it is probable that some of that stress is related to nurses' experiences of patient death and to their own attitudes to death and dying, for, according to Lazarus and Folkman (1984),

experience and personal beliefs or attitudes would both contribute to the appraisal part of the stress process. It is essential to understand what elements of the experience of patient death cause the nurse to make an appraisal of threat or challenge and which of those elements may be changed to render the situation more 'manageable'. The Lazarus and Folkman (1984) model of stress refers to 'management rather than mastery' in situations where it is impossible to change the situation to eliminate the stressor. In nursing, particularly when the patient is terminally ill, it is management which is required, for mastery has become an impossible goal.

Alexander and Ritchie (1990), in a survey of palliative care nurses, found that nurses experience greater levels of stress from dealing with patients whose pain is intractable, who have young children and who are afraid to die. It seems readily understandable that nurses' would feel distress at being unable to help someone in intractable pain. However, this difficulty in dealing with intractable pain is also said to be linked to the expectation of the nursing role in our culture. Fisher (1991), like Vachon (1987), concluded that nurses often have unrealistic expectations about what medical care can do, which may affect the amount of stress experienced in dealing with patient death. According to Fisher, nurses in palliative care situations have come to expect that all suffering should be relieved and tend to feel that they have let their patients down or that they have 'failed' if they do not succeed in that aim. Symptom-relief is an important part of providing a good death, beliefs about which are reviewed below.

It is undoubtedly an emotionally taxing role to care for someone who is about to die, leaving young children without a parent. This may be a situation which would increase the likelihood of the nurse identifying closely with the patient, for many nurses have young children or grandchildren of their own.

### 1.3.3 - The Good Death

The concept of good death is sometimes used to refer to euthanasia (Davis and Slater, 1989) but is more often associated with 'patterns or styles of dying' (McNamara et. al., 1995). Bradbury (1993) concluded that there is, in contemporary society, no all-embracing definition of 'good' or 'bad' death but that there were several variations of meaning given to the terms. However, she claims that those meanings fall into three broad

categories - the sacred, natural and medical types of 'good' or 'bad' death. The **sacred** 'good' death encompasses the death where the clergy attends, the dying person makes the relevant farewells and dies with dignity and acceptance of the inevitable fate. Bradbury claims this type of 'good' death is linked to the belief in the afterlife and the rebirth of the dead. The **natural** 'good' death category seems to include deaths which are sudden, free from pain and free from medical intervention.

Particularly relevant to this work, and bearing some similarities to natural 'good' death, is the **medical** 'good' death. This definition is said by Bradbury (1996) to be the dominant representation of modern society, at least in this western culture. The major requirement for a 'good' death in this category is the freedom from pain, derived from the period in history when opiates allowed doctors to manage the dying process and, in so doing, to usurp the role of the clergy at the deathbed. Bradbury argues that this desire for the painless death has led to excessive medical interventions which, in turn, have led to a rejection of medical science and the acceptance of the natural 'good' death. Bradbury concludes from her research that meanings of good or bad death "are temporally and culturally specific" (p94). The importance of culture is emphasised by Firth (1996) in her descriptions of the Hindu good death which has a sacred basis.

An awareness of the different definitions or kinds of 'good death' highlights the need for some caution in generalising research findings within this area of study. Data, generally qualitative, are usually gathered from small samples, either of dying patients or bereaved families. The ideas expressed by individuals under such difficult circumstances, though informative and highly poignant, must be highly individualised and therefore must be treated with some caution. Further, interviews with professional health-carers, wherein they are asked to describe their ideals and aims (their view of the good death), are likely to be coloured by some measure of professional vested interest. Nevertheless, as can be seen below, the importance of the literature is strengthened by the considerable consensus to be found across studies, in terms of the understood meaning of a good death.

From their studies of dying patients, Glaser and Strauss (1968) highlighted issues relating to awareness of impending death. Kubler-Ross (1969) emphasised the importance of acceptance of impending death. Largely on the basis of their work, awareness, acceptance and preparation for death have been established as the necessary elements for a 'good'



death (McNamara et al., 1995). Zimbleman (1994) claims that, for many people, the idea of a 'good death' is as important as the idea of a 'good life'. His description of the 'good death' includes time to make farewells but without prolonged suffering and death without physical, emotional or spiritual decay which robs one of dignity. Further, he states that most of us do not reject medical technology in its attempt to support or help during illness but a 'good' death is one "absent of heroic treatment that is futile or that prolongs our life when there is no chance of any meaningful interpersonal or spiritual existence" (p 22). Finally, a 'good' death in Zimbleman's terms means one which will not create undue difficulties for the bereaved in the remainder of their lives.

While it is ultimately the patient who dies, s/he does not usually die in isolation and the experience of that death must have some effect on those who have been involved in the care of the patient or present at the death. Nimocks et al. (1987) highlight this with the definition of goodness of death as "the extent to which the interactants accept the impending death, receive mutual emotional care and support, mitigate the dying person's discomfort and isolation and complete all 'unfinished business' (p 329). This definition would suggest that, in order to 'produce' a good death, all interactants should have the same understanding of what constitutes a good death.

Nurses' understanding of the concept of 'good' death is undoubtedly informed and shaped by social and historical aspects of the culture within which they live and work, and especially so if they work within the hospice movement. Hospice nursing, aiming to provide a complete person-centred holistic care, is based on philosophies which embody the concept of 'good death', conceptualised as a series of events which involves the family and carers as well as the dying patient (McNamara et al., 1995). Generally nurses believe that a 'good' death should include nursing care, effective symptom control and a pain-free, peaceful and dignified death. Hunt (1992) concluded that, while the quality of life prior to death was also an important consideration, nurses' considered symptom control, acceptance by patient and family of diagnosis and prognosis, and a peaceful death at home to be the components of the 'good death'. Although her research may be criticised because it was based on a very small sample of five symptom-control nurses who worked in patients' homes, Hunt's emphasis on dying at home concurs with Kubler-Ross' (1969) ideals.

McNamara et al. (1995) found evidence that nurses sometimes differ on the importance of some aspects of the care perceived to be necessary to a 'good' death. Symptom control may be essential to one nurse, but another may wish to allow patients to make their own decisions and may be more conscious of the need to allow the patient to dictate what, for them, will be the 'good' death. The literature suggests that there may also be differences of opinion, between health professionals and bereaved families, about whether a death has been good or bad (Bradbury, 1996). Bradbury contends that professionals may impose their concepts on the bereaved but that the effect is only temporary and families will come to their own decisions about the nature of the death. More importantly, however, a health-care professional's own concept of good death will influence how they care for both patient and family before death and for the body and the bereaved after death. Kelner and Bourgeault (1993) suggest that health care professionals must accede greater control to patients in making decisions about dying.

Some concerns have been expressed about the difficulties of maintaining hospice ideals of the good death in the face of increased bureaucratisation (Seale, 1989; James and Field, 1992; Biswas, 1993). It is also possible that increased use of technology and invasive forms of treatment may threaten the original ideals of hospice care (McNamara et al., 1994). If changes in organisational structures or settings make it impossible for professionals to maintain these ideals, there are implications, not only for patient care, but for nurses whose practice is led by those ideals.

If, as is the case with most nurses working in palliative care, nurses are committed to the delivery of care which meets the criteria of hospice ideals for the good death, that commitment will be a major factor in determining how nurses appraise the experience of patient death in terms of stress. This has been shown by McNamara et. al. (1995) in their findings that, within their Australian sample, stress for the hospice nurse is often the result of tension between the nurse's ideals and his/her ability to meet those ideals. It is likely that nurses in other settings will have their own concepts of what constitutes a good death and their cognitive appraisals (in terms of stress) of the experience of patient death are likely to be affected in the same way.

## **1.4 - Consequences of Stress**

This section will review the literature on the consequences of stress which include the impact on physical and psychological health and behaviour, with attention to nurses' reactions to stress. The phenomenon of burnout is defined and discussed in relation to nurses. This is followed by an outline of the previous work on the proposed phenomenon of 'accumulated loss' which is said to be related to the frequent exposure to patient death. Finally, this section reviews some of the factors which may influence reaction to patient death, with attention to the work of Parkes (1986,1996) and comments briefly on consequences for organisations of nurses' stress.

### **1.4.1 - Reactions to Stress**

From the beginning of stress research, it has been recognised that the consequences of exposure to stress, especially severe or prolonged stress, are often detrimental, resulting in distress for the individual. Symptoms of distress may be physical, psychological or behavioural (Sutherland and Cooper, 1990) and bearing in mind the process of stress, including feedback and reappraisal, symptoms may actually become stressors. A nurse who feels stressed by having too many patients to care for may respond by showing anger or frustration and this reaction may increase his/her stress because of feelings of failure to maintain professional image.

The acceptance that psychological stress has a detrimental effect on health is widespread in the literature. Stress and the ability to cope with it have been implicated in the development of diabetes mellitus (Cox et al., 1984), in increased incidence of death from coronary heart disease, particularly after bereavement (Parkes et al., 1969), in bronchial asthma (Weiner, 1977) and even in the development of cancer (Cooper, 1988, Cox, 1988). Psychosomatic illness and psychological disturbance are now recognised as possible consequences of exposure to stress and include headache, insomnia and neuroses (Cox, 1978). Some of the behavioural responses to stress, which include excessive use of food, tobacco and alcohol (Cox, 1988), may also have implications for health (Sutherland and Cooper, 1990).

Evans et al. (1997) claim that “there is now absolutely no doubt in scientific circles that our psychological experiences can influence the activity of our immune systems” (p303). Kasl et al. (1979), in their study of the development of infectious mononucleosis in West Point Cadets, concluded that there were significant relationships among psychological stressors, measures of immunity and health outcomes. Endresen et al. (1991), studying self-reported stress in relation to measures of cellular immunity (T-cell responses), report associations between numbers of T-cells and work stress among 94 Norwegian female bank employees, supporting the link between immune system activity and stress. Cox (1995) cites several other Norwegian studies which also support this link. However, in their review of the current issues in psychoneuroimmunology, Evans et al. (1997) demonstrate that the evidence does not yet provide definitive answers to some questions. An important anomaly is that some studies show increased immune system activity in response to acute stressors (Delahanty et al., 1996, Evans et al., 1994), in contrast to studies which show a decrease in immune system activity in response to chronic stressors (Evans et al., 1993, 1995). Evans et al. (1997) conclude that, while acute stressors may sometimes enhance immune system activity, chronic intense stress, particularly that associated with personal relationships, may be linked to serious impairment of immune response. This, in turn, may have implications for health outcomes.

#### 1.4.2 - Nurses' Reactions to Stress

The comprehensive study by Vachon (1987), of stress among caregivers who work with the critically ill, the dying patient and the bereaved, demonstrated the wide range of manifestations of stress. Vachon reports that stress “may be manifest in physical, psychological or behavioral symptoms” (p 137), although the majority of symptoms of stress reported within her sample were either psychological or behavioral. As a result of quantifying the qualitative data, depression, guilt, grief, staff conflict, conflict between work and home which included marital and family conflicts arising from work-related matters, feelings of helplessness or inadequacy and anger are reported as accounting for 63 percent of the manifestations of stress found by Vachon. However, minor illnesses including constant fatigue, headaches, backache, and gastro-intestinal problems were reported to be stress-related, as were the more serious illnesses such as hypertension, ulcers, anorexia, Crohn's disease and incapacitating headaches (migraine and cluster types). It must be remembered, however, that this evidence is based on qualitative self-

report data and while attributed, in Vachon's study, to stress, the evidence for causality of these illnesses may be disputed.

In other studies of occupational stress in nursing, links have been made between stress and low job satisfaction and high turnover (Gray-Toft and Anderson, 1981b), negative mental health outcomes as measured by the General Health Questionnaire (Goldberg, 1972) by Tyler and Cushway (1992) and Tyler et al. (1991) and burnout (Sullivan, 1993).

#### 1.4.3 - Burnout

Cherniss (1980) stated that "burnout is a reaction to a stressful work situation" (p 13). He concluded that burnout is a transactional process comprising three stages, beginning with severe and prolonged stress, moving to the effect on the individual, or 'the strain' and resulting in what he called 'defensive coping'. Defensive coping is characterised by emotional detachment, cynicism and a loss of commitment. The latter two elements, or the effects of the severe and prolonged job-stress, have been the focus of work by Maslach and Jackson (1981). They propose that the consequences of chronic occupational stress, particularly in those occupations where the job entails working with people and where there is a high level of emotional involvement, may be the development of a phenomenon known as burnout. They state that:

"Burnout is a syndrome of emotional exhaustion and cynicism that occurs frequently among individuals who do 'people-work' of some kind. A key aspect of the burnout syndrome is increased feelings of emotional exhaustion. ... Another aspect is the development of negative, cynical attitudes and feelings about one's clients. .... A third aspect ...is the tendency to evaluate oneself negatively, particularly with regard to one's work with clients." (p 99)

The syndrome as described by Maslach and Jackson (1981) has been widely accepted in the literature. The research literature also reveals widespread use of these authors' measure of burnout (The Maslach Burnout Inventory, MBI, 1981), especially among human service workers (Ceslowitz, 1989; Boyle et al., 1991; Bennett et al., 1994). Burnout is seen as a continuous variable which may be found in low, moderate or high degree in individuals. It is not a dichotomous variable wherein an individual either does or does not suffer from burnout (Maslach and Jackson 1981).

The consequences of burnout are severe according to the extensive research carried out by Maslach and colleagues during the 1970's and 1980's and cited in the Maslach Burnout Inventory Manual (1986). Maslach and Jackson (1986) suggest "that burnout can lead to a deterioration in the quality of care or service provided by the staff" (p 2). Their research has also linked burnout to job turnover, absenteeism, low morale, and personal dysfunction including insomnia, substance abuse and marital problems.

One of the caring professions where occupational characteristics would predict the strong possibility of higher levels of burnout is nursing where great demands are made on the carer. Further, in certain areas of nursing where the emotional intensity of caring for others is greatest, such as in critical care and in hospice nursing, the potential for burnout may be even greater. To reiterate, many studies have reported that 'death and dying' is a common source of stress for nurses (Gray-Toft and Anderson, 1986-1987; Vachon, 1987; Tyler et al., 1991). Repeatedly being in contact with the dying is also reported to be associated with increased vulnerability to burnout (Munley, 1985; Marquis, 1993). That being the case, one might expect that palliative care nurses would demonstrate higher burnout scores than the nurses from psychiatric or general nursing areas. Mallett et al. (1991) in an American study report that hospice nurses had lower levels of burnout than critical care nurses, a finding which was attributed to better coping practices, more autonomy in their work and stressors being organisational in nature rather than related to clients and families. However, previous studies have shown that while sources of stress do tend to differ across groups of nurses, the levels of stress do not (Foxall et al., 1990; Tyler et al., 1991). Since burnout is said to be the effect of stress, it is reasonable to suggest that there would be little difference in burnout levels.

#### 1.4.4 - Accumulated Loss Phenomenon

The concept of 'accumulated loss' has been addressed by Adams et al. (1991) who suggest, from their own experiences, that hospice nurses suffer from something which differs from burnout, insofar as it relates specifically to the accumulation of feelings of loss because of frequent patient death and the lack of opportunity to grieve. Little research has been focused on this concept of accumulated loss. It is, however, an area of growing importance in view of the increasing numbers of elderly in our population, the growing

numbers of HIV and AIDS patients who will require care and the tendency of nurses to be in the front line of care for the dying, whether in hospital, hospice or at home. Nurses, more than most other carers, must frequently cope with the death of people they have come to know. In some clinical areas, especially in hospice work, patient death may occur daily or more often. This means that there may be little time for the nurse to deal with his/her feelings about one patient's death before coping with the next death (Adams, 1989). Saunders and Valente (1994) also argue that encountering multiple deaths makes it more difficult for nurses to manage their own grief.

The hypotheses proposed by Adams et al. (1991) were a) "a phenomenon exists among hospice caregivers which can be identified and described", b) "there is a relationship between the length of time worked (in years) in a facility and the acuity of experience or reaction", c) "there is a relationship between the number of hours worked per week (in a facility) and the intensity of the reaction", and d) "there is a relationship between the profession of the caregiver and the reaction". To gain information about these hypotheses, they used a questionnaire to survey 100 hospice care-givers.

On the basis of responses to that survey, Adams et al. (1991) stated that "Accumulated loss phenomenon results from an overexposure to the actual and idealized process of dying and death on a daily basis. This experience results in a set of unique characteristics by which care-givers develop certain behaviours, both positive and negative" (p 30). Accumulated loss phenomenon is said by Adams et al. to have five basic characteristics: lack of closure, dying and death concerns, ideals vs reality incongruity, identification-distancing and diminished boundaries.

Lack of closure is said to be a perceived emotional void which results from a lack of sufficient opportunity to cope with patient death and bereaved families. Dying and death concerns refer to thoughts and anxieties about illness, disability and death (either personal or imagined). Ideals vs reality incongruity is related to feelings about what is the desired and what is the actual clinical practice. Identification-distancing reflects the psychological or physical attempt to separate oneself from the realities of clinical practice, and diminished boundaries accounts for the blurring of personal and care-giving commitments.

Some aspects of what has been called 'accumulated loss phenomenon' appear to be similar to those associated with burnout, ie depersonalization - distancing, emotional exhaustion - emotional void (said by Adams et al. to result from lack of closure). The question arises as to whether there exists a specific accumulated-loss-related phenomenon which is found only among hospice nurses working where there is a very high death rate among patients, or whether this is simply burnout among hospice nurses. It is no doubt a much more complex question than is apparent in the paper published by Adams et al. (1991) who recognize the need for further research. An additional question might be whether, if the phenomenon does exist, it might be found among nurses in other units where death is a frequent visitor and not only among hospice nurses. In the absence of published work which replicates the Adams et al. study, these important questions remain unanswered.

In this study, one of the aims is to investigate the evidence of the phenomenon described by Adams et al. (1991), using a sample which includes nurses from palliative care as well as from psychiatric and general nursing areas. That evidence will be compared with the results of a measurement of burnout within the same sample of nurses. This may help to answer the question of whether burnout is a sufficient concept for the phenomenon which afflicts some nurses (and/or perhaps others in the caring professions) who become unable to continue to make the emotional investment which is required to nurse effectively. Both quantitative and qualitative data will be gathered to determine the effects of working with dying patients and reactions to patient death.

#### 1.4.5 - Factors Which May Influence Reaction to Patient Death (a potential stressor)

It is reasonable to expect that being present at the deaths of patients must have some effect on personal attitudes. Fisher (1991) has stated that working with grief and bereavement touches us by making us aware of our own losses and by increasing our concern about our own potential or feared losses. Although Field (1989) suggests that contact with dying people may reduce nurses' own fear of death and dying, caring for patients who are afraid to die may also have the effect of raising the level of personal fear of death and dying in the nurse. Among health professionals, personal fear of death is said to be related to anxiety about dealing with dying (Glaser and Strauss, 1965; Howells and Field, 1982).



Parkes (1996, p119-120) has listed the determinants of the outcome of bereavement under three headings. 'Antecedent' includes previous experience, relationship with the deceased (in terms of attachment strength, involvement, and intensity), and the mode of death (timeliness, expectedness, violent deaths, culpable deaths and losses which cannot be openly acknowledged (for example a homosexual lover, a mistress or even an instance where a nurse has become attached to a patient). 'Concurrent' includes personal characteristics such as age, sex, religion and cultural factors which may affect the expression of grief. 'Subsequent' determinants of outcome include social support or isolation and other stresses. It seems likely that these factors will also affect the nurse's reaction to patient death.

### Antecedent Determinants

Because of the emotional investment the nurse must make while caring for the patient, there is the potential for a relatively strong bond of attachment to develop between nurse and patient (Fisher (1991). This may be emphasised in palliative or hospice units where caring may include some very unpleasant tasks. The nature of the attachment may also be affected by the length of time a nurse has known a patient, the involvement with the patient's family, the age of the patient and the extent to which the nurse identifies with the patient. This raises some questions about differences in the nursing experience. For example, does a psychiatric nurse develop similar attachments to patients? Are there factors in the psychiatric nursing experience which make patient death a different experience from that of other nursing areas? While patient death may be experienced less frequently in the psychiatric wards, nurses need to be prepared to cope with the event, should it happen. For some areas of psychiatric nursing, patient death may more often be the result of suicide. This may raise reactions and feelings in nurses which differ from those experienced in elderly dementia units or in other clinical areas of nursing. A German study (Heydt and Potschigmann, 1989) reported nurses' wishes to learn how to deal with feelings of guilt and inadequacy which resulted from patient suicide. A greater understanding of the nurses' experience of patient death in psychiatric care would help to increase our understanding of the needs of psychiatric nurses in this regard.

The experience of patient death no doubt varies widely among nurses. Parkes (1986, 1996) has stated that the nature of the death, for example, whether a sudden death or a

death which has been expected, influences the grieving process of the bereaved. Vachon et al. (1980) support this idea. Their work was largely based on research with bereaved family members. Vachon (1987), however, also reported that nurses found 'unexpected' deaths more difficult to cope with. Unexpected deaths included sudden death, often from accident or from coronary disease, suicides or homicides and the death of young patients but also included such tragic scenarios as the diagnosis of terminal cancer in a pregnant woman.

### Concurrent Determinants

Parkes (1986,1996) has included age, sex, religion and cultural factors which may affect the expression of grief in the list of determinants of the outcome of bereavement. These factors are individual characteristics but the cultural factors which may affect the expression of grief, are particularly pertinent to **groups** of individuals. Within the nursing culture, there are attitudes, or rules, which may play a part in the way nurses deal with patient death. Even though the expression of emotion is understood to be an effective way to resolve grief, professional nursing education tends to emphasise the need for composure and control of feelings, especially in the presence of patients or the public (Eakes, 1990; Katz, 1996).

Cultural factors are, to some extent, specific to the different clinical settings and affect how nurses do their work (Field, 1989). These cultural factors include: disclosure norms (the amount of information given to patients which may be especially significant if the patient is dying and the patient has not been made aware of the prognosis), characteristics of the client population ( death on an elderly care unit may raise different emotions from that in a surgical unit where patients may be of mixed/younger ages), nurse/doctor relationships (the level of autonomy negotiated between nurses and doctors) and the overall style of nursing in the unit (the level of warmth and friendly, caring atmosphere which may be highly dependent on those staff members who are in charge of the units) (Field, 1989). All of these factors are likely to have some effect on how nurses react to patient death and how they express their grief.

These differences may be more marked between hospice units and other settings because of the different purpose within hospices, that of caring almost exclusively with terminally

ill patients. The team approach to staffing and higher nurse/patient ratios found in most hospices (Field, 1989) may have a beneficial effect on how nurses react to death because of the availability of support from colleagues. However, the high incidence of patient death within palliative care units may also have an accumulative negative effect on staff as proposed by Adams et al. (1991). This study, using nurses from palliative care (including hospices), psychiatric and general nursing units allows comparison, across the three clinical areas, of nurses' reactions to patient death and of their perceptions of their ability to cope with death and dying issues.

### Subsequent Determinants

Those factors labeled by Parkes (1986, 1996) as 'subsequent', social support, isolation and other stresses, are important in the process of coping with any stressor (Lazarus & Folkman, 1984). Lower burnout scores have been linked to adequate social support by Ceslowitz (1989) in hospital staff nurses, and by Boyle et al. (1991) and Schaefer and Peterson (1992) in critical care nurses. Vachon (1987) has also described the importance of good social support, in coping with stress, in her study of nurses, doctors and other carers of the critically ill and dying.

Holman (1990) has argued that professionals who are frequently exposed to death are vulnerable to high levels of anxiety and may use death denial as an avoidance mechanism, becoming psychologically unable to support their dying patients. Undoubtedly, if nurses are faced with multiple sources of stress, there is a potential for difficulty to arise with coping. Nurses who experience many patient deaths may be at risk of a poor outcome of bereavement or negative effects of the related stress (Adams et al., 1991).

### 1.4.6 - Consequences for Organisations and Patients

If work-related stress has consequences for the nurse, it also has consequences for nurses' employers and for their clients. It has been claimed, by nurses' union officials (Mowbray, 1995), that the National Health service loses 24 million pounds per year in absenteeism due to stress and demoralisation among nurses. In an organisation which is stretched to maintain levels of service within shrinking budgets, this must mean serious implications for the product - patient care. It is impossible to disprove such a claim by separating out

specific causes of absenteeism, or, as discussed above, to be definitive about sources and levels of stress.

However, it is likely that, in terms of standards of care, there must be consequences for the patient. If professionals are unable, through the effects of stress, to give psychological care to dying patients (Holman, 1990), withdraw from patients to avoid more stress (Vachon, 1987) and become excessively detached from the people in their care (Maslach, 1993), then standards of patient care must be affected.

## **1.5 - Influences on Coping**

The following section briefly discusses coping definitions and the literature on how nurses cope. This is followed by a review of the literature on death attitudes, with particular attention given to fear of death, coping with death and death self-efficacy which may be important influences on the ways in which nurses cope with patient death.

### **1.5.1 - Coping**

It is impossible, and even undesirable, to avoid all forms of stress and for most people, the most important concern is how to cope with a stressful situation. 'Coping' is a concept which, like stress, requires clear definition. Pearlin and Schooler (1978) say their use of 'coping' refers to "the things that people do to avoid being harmed by life-strains" (p 2). A more specific definition is given by Lazarus and Folkman (1984) who define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person"(p 141).

There are four main points which are inherent in the latter definition. Lazarus and Folkman see coping as a process involving changing efforts to deal with specific problems. This process requires effort and is related to specific demands (those which are appraised as taxing or exceeding resources). Coping is different from outcome. Coping is the effort to manage but outcome is the resulting effect of that effort. Finally, the word 'manage' is used to express the idea that one is not always able to master the environmental stressor. Hence, managing the stressor may include avoiding it, reducing it, or ignoring it.

Folkman and Lazarus (1980) used the terms 'emotion-focused' and 'problem-focused' coping to refer to the two main types of coping discussed by Pearlin and Schooler (1978). Emotion-focused coping refers to efforts made to manage or control the emotional responses to a stressor and includes a range of cognitive processes, some of which may actually change the way an individual appraises the situation. Emotion-focused strategies include finding some positive aspect of a situation, minimizing or changing the importance of some aspect, selective attention, avoidance and distancing. Problem-focused coping is aimed at controlling or changing the actual situation which is causing the stress. This may be accomplished by using problem-solving skills (deciding what the problem is, looking for possible solutions, deciding which alternative is the best and acting on it). However, some problem-solving coping may be aimed at the person rather than the environment. For example, if the need or desire to achieve a certain goal is the source of the stress, it may be necessary to change the goal by lowering one's ambitions or by redirecting one's focus of interest (Lazarus and Folkman, 1984).

The role of cognitive appraisal is as important in coping as it is in determining whether a situation is stressful. An individual needs to consider what coping strategies are available, which would be appropriate and/or effective and whether they are able to carry out the strategies. A person's perception of what resources are available to help in the coping process may not be the same as what is actually available but it is the perception which will direct the person towards a certain coping strategy. Coping resources may include material resources such as money to buy goods or services, but also include person characteristics such as physical health, self-esteem, or skills such as problem-solving, social or professional skills and training (Lazarus and Folkman, 1984). Social support has also been shown to be a valuable resource in coping with stress (Cobb, 1976; Cohen and Wills, 1985).

Research into how nurses cope has often been a part of the research on stress, as with the work of Vachon (1987). Her extensive study of those who work with the terminally ill identified a wide range of strategies including developing personal philosophies about their roles or about illness and death, having strong support systems (social support), avoidance and distancing oneself from the patients, and having a sense of humour, as well as organisational or administrative strategies such as formalising decision-making, job-

flexibility and training. Ceslowitz (1989) reported that planful problem solving, positive reappraisal and seeking social support were used by nurses with lower burnout scores, whereas escape/avoidance and confrontation were used by those with higher burnout scores. Emotion-focused coping strategies, such as wishful thinking and distancing, were also reported, by Boyle et al. (1991), as positively related to burnout. Schaefer and Peterson (1992) found that critical care nurses reported confrontive (priority setting or problem solving) and supportive (using counselling or support groups) coping strategies to be most effective.

These studies demonstrate that nurses use a range of coping strategies, some of which are more effective than others. It is not clear from the literature whether nurses choose specific coping strategies for specific situations. For example, it is unclear whether they have special strategies for coping with patient death, although O'Hara et.al. (1996) report that twenty percent of their sample reported no strategy for dealing with patient death.

This study will explore nurses' use of different coping strategies and their effectiveness, with an emphasis on coping with patient death. In the perspective of stress proposed by Lazarus and Folkman (1984) an individual's ability, real and/or perceived, to cope with patient death will be affected by their perceptions about availability and effectiveness of coping resources as well as their beliefs and attitudes about the event itself. In attempting to understand more about nurses' reactions to patient death and abilities to cope with such an event, it is important to gather information about nurses' attitudes to death.

### 1.5.2 - Attitudes to Death

The apparent importance of death and dying issues as sources of stress felt by nurses suggests a need to study some of the attitudes to death held by nurses. As has been stated above, nurses are expected to cope competently with death and dying issues. It has been alleged that nurses who are unable to face death on a personal level will project their personal fear onto their clients and will be less able to meet the needs of dying patients and their relatives (Cundey, 1981). Therefore it is important to understand about levels of fear which nurses feel and whether nurses actually perceive themselves to be competent to cope with this aspect of their work and/or with death and dying issues which may touch their personal lives.

There is a relatively large body of literature on death attitudes, most of which has originated in the United States of America. Research has been carried out on death anxiety (Templer, 1976, 1970; Templer et al., 1971; Nelson and Nelson, 1975), death depression (Templer et al., 1990; Alvarado et al., 1992-93), death concern (Dickstein, 1972), and fear of death (Lester, 1990; Collett and Lester, 1969). There is some apparent difficulty in determining exactly what is being studied and how each of these concepts differs from the other. Durlak and Kass (1981-82) report on their factor analytic evaluation of fifteen self-report measures of death attitudes. They concluded that there were at least five death-attitude factors apparent in their survey sample. These were named 'negative evaluation of death', 'reluctance to interact with the dying', 'negative reaction to pain', 'negative reaction to reminders of death', and 'preoccupation with thoughts of dying'. They suggest that this work supports thanatological theory that death attitudes are multidimensional and that several death attitudes may co-exist and co-vary within individuals. Neimeyer (1994) has also expressed the need for multidimensional approaches to death attitudes.

Death anxiety has been the most widely researched concept and much of the work is reviewed by Lonetto (1986). His discussion of the correlates of death anxiety concludes that there is little evidence of a relationship between death anxiety and age except among very elderly populations where an inverse relationship is sometimes found. Religion appears to be a factor only among those groups who are deeply involved in religion and results do not differ significantly across different religious denominations. Lonetto (1986) contends that depression and psychopathology appear to be related to death anxiety and there may be a link between higher death anxiety and external locus of control. Results are mixed on a host of other potential factors including race, rural versus urban populations, married versus single states, and personal experience of loss. Lonetto cites Whittenberg's (1980) unpublished findings, related to a study of nurses from four groups (medical, medical/surgical, surgical and intensive care). Whittenberg found no significant difference in death anxiety scores as a function of clinical area, or as a function of the number of terminal patients in their care over a recent period or whether or not a patient death had been witnessed. However, Brockopp et. al. (1991) concluded that nurses who work with the dying on a continuous basis experience lower levels of death anxiety than those who do not. While Hoelter and Hoelter (1980-81) acknowledge the need to treat their findings

with some caution (because of the relatively small proportion of their sample which had been exposed to death), they report exposure to death to be positively correlated to fear of the dying process and fear of premature death in their study of 375 undergraduates. Undergraduates' experiences of death and dying related to the deaths of friends or relatives, whereas nurses' experience includes the deaths of patients with whom their emotional ties or bonds would, presumably, be different from bonds with close friends or family members. While this makes the two samples different in that respect, it is difficult to assess the impact of that difference.

There is some published research regarding death attitudes and nurses (Mallett et al., 1991, Divers Korte 1985, both US studies). Mallett et. al., in a national sample of 376 hospice and critical care nurses, found higher levels of death anxiety among the nurses in critical care. Divers Korte reported lower levels of death anxiety in older nurses and in those who had more years of experience. Death anxieties among staff in residential care settings for the elderly were studied by Robbins et al. (1992), in the UK, where age appeared to predict levels of death anxiety. Also in the UK, fear of death in medical trainees (Firth-Cozens and Field, 1991; Howells and Field 1982; Howells et al., 1986) has been researched (see below). The lack of clarity of meaning in 'death concern' and 'death anxiety' and the use of different instruments makes comparisons of results of these studies somewhat tenuous. Further, without some baseline measure of what attitudes exist within general population samples, it is difficult to assess whether death attitudes of these health professionals are relatively positive or negative.

### 1.5.3 - Fear of Death

The 'Fear of Death' scale (Howells et al., 1986) represents a much clarified approach to the question of fear which is related to death and dying. In this scale each of four direct questions relates to one aspect of fear of death. There is no suggestion from the authors of the scale that these questions cover all dimensions of 'fear of death'.

The question arises of whether and/or how nursing experience may affect the levels of fear of death felt by nurses. Howells and Field (1982) could find no difference in death attitudes between first-year medical students and non-medical students. Further, in a study of first-year and fourth-year medical students, Howells et al. (1986) concluded that



there was only limited support for the idea that the clinical experience gained by fourth-year students had increased fear of death in medical students. Firth-Cozens and Field (1991), in a longitudinal study of medical students and using the Howells et. al. approach to measurement of fear of death, found that during their four year training which included clinical experience of patient death, there was a small, though insignificant, decrease in fear of death and that psychological well-being (measured by the General Health Questionnaire - 12) was significantly related to fear of death scores, but correlations were very small.

Though the roles of medical students and nurses have much in common, there are differences in both amount and content of time spent with the dying patient. Nurses experience the emotional trauma of illness and death with patients and families at first-hand, usually spend more time with patients and families and are very often present during the actual process of death. Therefore, one might expect that the nature and frequency of nurses' clinical experience would have a more marked effect on fear of death and on the basis of Firth-Cozens and Field (1991), that effect should be a greater decrease in levels of fear.

Although Howells et al. (1986) state that "trait fearfulness is a product of both the intensity of fear and the frequency with which fearful reactions arise" (p 503), it is worth considering that even though one may fear an event, one may also think about some aspect of that event without necessarily experiencing fear. In the case of fear of one's own process of death, is it possible that a nurse, experienced in the care of the dying, may gain reassurance from watching others die in a comfortable and peaceful manner? Honeybun et al. (1992) and Payne et al. (1995) found that hospice patients who witnessed the death of another patient suffered less depression and reported some comfort from the experience. Would the experience reduce fear of the process of dying for the nurse as s/he possibly considers the potential for his/her own death being comfortable and peaceful? A major aim of palliative/terminal care, especially in hospices, is to provide symptom relief and care which allows the patient to die without physical or psychological pain or distress (Dobratz, 1990). This is not always emphasized to the same extent in other areas of nursing, so the question arises as to the effect of particular clinical areas of work on fear of death. Generally, previous research suggests that the palliative nursing group in this study, who would be expected to have the highest level of clinical experience of patient death, should

have lower levels of fear of death than the other two groups and lower than those of the general population sample.

The importance of learning more about how nurses react to patient death is highlighted by evidence that personal reactions to stressful situations may affect how nurses and doctors actually care for their patients (Glaser and Strauss, 1968; Vachon, 1987). For example, Vachon found that errors in judgement about treatment were reported by doctors who worked in very stressful casualty units. While it may be considered desirable and correct, in professional terms, for a nurse to hide or control personal reactions, it is almost certainly unrealistic to expect a nurse to work in highly emotional and stressful situations, such as nursing a dying patient, without experiencing some personal reaction. If a nurse carries a high level of personal fear associated with some aspect of death, and is engaged in nursing a dying patient, it is possible that the fear may have some impact on how the nurse deals with that work and with that patient. Cundey (1981) asserts that nurses will project their own fears onto their patients. Similarly, it could be argued that the work may impact on the nurses' levels of fear. A greater understanding of nurses' fears associated with death and dying would help to inform nurse educators, nurse managers and nurses themselves.

To understand these fears, they need to be viewed in a proper perspective and it is important to have a base line with which they may be compared. A survey of levels of fear of death among members of the general population would help to provide that base line. On the basis of findings of Firth-Cozens and Field (1991), that clinical experience lowered levels of fear, nurses' levels of fear of death should be lower than those of the general population sample.

#### 1.5.4 - Coping With Death and Dying

Coping with death and dying is a part of life for everyone, if only limited to dealing with one's own mortality. In work on 'coping with death' (Bugen, 1980-1981) and 'death self-efficacy' or 'death competency' (Robbins 1992), it is, as Robbins says, clear that people do 'cope' with death and dying. However, nurses, by the very nature of their professional role, are expected to cope more frequently than most other people, to 'cope' competently and to help others cope. In an unpublished study (McNeely 1993) nine out of 27 nurses said they did not feel that their training had adequately prepared them to communicate

with a dying patient, eight felt inadequately prepared to communicate with relatives and ten said they were inadequately prepared to cope with their own feelings about death. Kelsey (1992) found a similar lack of confidence about their training and skills among nurses in his sample.

The process of secondary appraisal includes the assessment of what coping strategies are available and how effective they are likely to be (Lazarus and Folkman, 1984). In the case of a nurse dealing with death and dying issues or situations, coping strategies which might be considered to be available would include the skills and competencies to deal with practical nursing aspects, interpersonal skills to communicate with and address the needs of the patient and or families, and emotional skills and resources to cope with one's own feelings as well as those of others. If nurses perceive that they are competent to cope or have available the necessary coping strategies to deal with death and dying situations and related issues, then that perception of competence must reduce the likelihood that a potentially stressful situation will actually be appraised as stressful. In other words, according to the theory of Lazarus and Folkman (1984), if a nurse is able to appraise a death and dying situation as "challenging" or "benign" rather than "threatening" or "stressful", there is less likelihood of negative effects for the nurse. The possible implications for nurses' own emotional and mental health, for the quality of care given to dying patients and for the requirements of training of nurses are serious. An important question which arises is whether the lack of confidence in their competence to deal with death and dying is widespread among nurses. Further, is that lack of confidence evident, even among palliative care nurses who have had extra training in this area and for whom patient death is a very frequent occurrence?

The link between confidence in one's ability and competence in performance is widely accepted and an important element in any consideration of training or education of nurses. As Robbins (1994) has said, hospices are really promoting competency in dealing with death through their training of both professionals and volunteers. The aim is to promote, in carers, those skills required to help families and relatives as well as the patients to cope with both emotional and practical issues.

The issue of measuring competency in dealing with death and dying has been studied by Bugen (1980-81), with a view to assessing changes in results from before and after death

education seminars. His sample of 24 graduate and 30 undergraduate students completed the Coping with Death Scale on two occasions, at an interval of three weeks. During that time the graduate group had experienced a 15-unit death and dying course while the control group of undergraduates had been exposed only to two course units. Results indicated significant change over the three week period for the group having the full death education course. While Robbins (1990-91, 1992) accepted Bugen's claim that, within a sample of hospice volunteers, many of the items on the scale discriminated between the trainee volunteers and controls, she continued the validation work, using a larger sample of students ( $n=94$ ) and a sample of hospice volunteers ( $n=320$ ). On the basis of results from the two samples, Robbins declared the scale to be a reliable measure of death competency (see Chapter Two for reliability statistics). Among the hospice volunteers, scores on the Coping With Death Scale indicated higher levels of perceived competency among those carers who had more experience (all carers in this sample had been given the same training).

Bugen's Coping With Death Scale largely addresses the skills required to work in a hospice (which, by its nature, requires dealing with death and dying). However, Robbins (1992) wished to investigate competencies related to those and other death-related behaviours such as making a will or coping with personal loss. To that end, Robbins has investigated further, guided by Bandura's (1977, 1982, 1986) social/cognitive learning theory which encompasses the idea that learning in humans happens by way of both reinforcement and imitation. According to Bandura (1977), as ability to perform successfully increases, so does the individual's efficacy-expectation or belief in their ability to perform. The best sources of information for the learner about their self-efficacy are 'performance accomplishments' and 'vicarious experience' while the least informative is anxiety or arousal (Bandura, 1977).

An application of this theory would lead one to expect higher levels of perceived death-self-efficacy among those nurses who have had more specialised training and/or are very experienced in caring for the dying, and particularly among hospice nurses (as Robbins' (1992) work suggests). This would also suggest that those more experienced in dealing with death and dying would report less stress associated with death and dying. Yet, Foxall et al. (1990) reported that death and dying was more stressful for intensive care and hospice nurses than for medical-surgical nurses. This requires further attention and

research, but possible reasons for these differences may be related to characteristics of particular units in which the nurses work as well as to specific training issues.

Robbins (1991), in her study of death competency in college students, used the Coping With Death Scale in conjunction with a death anxiety scale, and reports significant negative correlation between coping with death and death anxiety. This is somewhat inconsistent with her findings with hospice volunteers (Robbins, 1992) which investigated coping with death, death self-efficacy and death anxiety among groups of long-term and medium-term hospice volunteers, trainee hospice volunteers and a control group of hospital volunteers. In that study, although there were significant group differences on both Coping With Death and Death Self-Efficacy, the death anxiety measure failed to show group differences. Although the former findings would be expected, it would seem to follow from the correlational relationship, that group samples in the second study would differ on all three measures. This too requires further study and clarification.

#### 1.5.5 - Death Education as an Aid to Coping

While the settings in which they work and their experience in those settings will affect nurses' appraisals of stress and their ability to cope, so too will the training and education which they have received. The nurse's repertoire of coping strategies available to deal with death and dying needs to include the professional knowledge and skills required to do the work but should also include the perception of an ability to cope with the emotional demands.

The educational preparation of nurses for the task of nursing the dying includes an increasing amount of time spent on death and dying topics. Death education appears to provide benefits which include reducing anxiety in nurses (Field 1986) and in medical students (Kaye, 1991) and making them more confident of their ability to care for the dying, although some concerns have been expressed by nurses about the gap between what was taught and actual experience on the wards (Field 1986). This reflects nursing schools' tendency to promote the idea of holistic care which includes emotional and social support as part of the nursing role, whereas the reality of ward nursing is more likely to be a task-oriented approach aimed at accomplishing a certain amount of work (Melia, 1987). Field (1989) suggests that because the informal, nurturing and loving kind of care is considered

to be a natural part of feminine behaviour, too little importance is assigned to teaching how to give that care. Further, on the wards, heavy workloads may create an emphasis on the medical care which is more visible and while the physical needs of the patient are attended, the psycho-social needs are ignored.

Kelsey (1992) reports that a considerable proportion of nurses still perceive themselves to lack skill in providing support to the patient and families. In Kelsey's sample, nurses trained during the last decade report greater difficulty in supporting relatives than those nurses who trained prior to 1980, when there was less death education included in nurses' training. Although he argues that this suggests that the modern nurse is more aware of the needs of the whole family, this finding may also suggest that older nurses, having more years of experience, have developed greater skill and confidence in this area of work. Durlak and Riesenbergs (1991) argue that experiential methods of teaching about death and dying were more effective than some others. This would suggest that actually doing the work would also be an effective way to develop the skills, an idea which is supported by Bandura's (1977) social learning theory.

Using the framework of Lazarus and Folkman (1984), one of the factors which will affect how a nurse appraises a patient death experience, in terms of stress, will be his/her perceived ability to cope with the situation. If the nurse feels adequately trained, this will be a major step towards feeling able to cope and as a consequence, the nurse will be less likely to appraise the situation as threatening. The nurse may still appraise the situation as challenging but adequate training should help to reduce the levels of stress (and harmful consequences) for the nurse. The issues of education and training for coping with death and dying appear to have received relatively little attention in the literature. This is another area where further research may be beneficial.

## **1.6 - Evaluation of the Literature**

Any critique of the research reviewed and summarized above must be prefaced by acknowledging that research into such subjective issues as stress, coping and fear of death is a difficult and often controversial endeavour. The 'individuality', discussed above in terms of the stress process, problems inherent in defining subjective phenomena, and the need for caution in interpretation of findings (further discussed in Chapter Two) apply

similarly to death attitudes and perceptions of fear. Some criticisms of stress research have been discussed in 1.2.3 and the following section will continue the discussion and criticism of the literature on stress, coping and death attitudes.

A reading of the literature on stress, coping and death attitude research reveals that many of the conclusions and findings have been based on self-report methods of collecting data. Briner and Reynolds (1993) and Sutherland and Cooper (1990) have criticised this reliance on self-report measures in stress research. However, if the cognitive models of stress, with the emphasis on the appraisal process, are to be accepted, then stress is a very subjective matter. If a person perceives an event as stressful, then, for that person, it is a stressful event, regardless of whether or not any other person finds that event a source of stress. This must surely give some credibility to the use of self-report measures in this area. This individuality of the process does, however, emphasise the limitations inherent in the use of cross-sectional studies in stress research, especially in the search for sources of stress. Nevertheless, there are many qualitative studies reported within social science literature, some of which are included in the literature review above, which demonstrate the richness of insight into human experience which has been gained from self-reports.

Many of the problems encountered within the research on stress are also to be found in the coping literature. An additional difficulty in the literature on coping is the lack of consensus on how to define and categorise coping strategies. Some researchers work under the headings of emotion-focused and problem-focused strategies (Ceslowitz, 1989). Others discuss in such terms as confrontational coping and supportive coping (Schaefer and Peterson, 1992). This makes comparisons of findings somewhat tenuous.

Sampling may also be considered a contentious issue in some stress and coping research. Conclusions are sometimes drawn from findings from small sample sizes, as in Hipwell et al. (1989) where a total sample of 65 nurses was actually divided over four groups which were compared. Findings gathered from nurses in one specialty unit are sometimes proposed to relate to nurses in general, as in Tyler and Cushway (1992), when factors specific to a particular area of nursing may be influential to results. Combined with the tendency of most studies to use a single methodology, usually questionnaires, this highlights the need to apply caution when generalizing findings in this area of research.

Thanatological research, particularly that related to death anxiety which is the concept most often studied in this broad area, has been highly criticised by Kastenbaum (1987-88). He claims that death attitude research is insufficiently underpinned by theory and that samples used in the study of death anxiety are too often opportunistic samples, rather than chosen on the basis of logic. He highlights the argument about the value and interpretation of high and low scores on measures of death anxiety: are low scores a sign of low death anxiety or a sign of denial and therefore high death anxiety? Further, he argues that many researchers in the field avoid contact with respondents and place too much emphasis on one self-report questionnaire. However, moderating his generally critical tone, Kastenbaum states that some findings from the death anxiety research have "...some value even if one continues to question the assumption that "death anxiety" is what these scales assess". The absence of consensus and acceptance surrounding research instruments (stemming, perhaps, in part, from the lack of widely accepted theory) and the confusion about what is being assessed in death attitude research are also highlighted by Durlak and Kass (1981-82).

Neimeyer (1994) warns that some caution is needed in the use of multidimensional approaches to death attitudes and the analysis and interpretation of results. He contends that one should not always operate on the assumption that, in research, each new measure or new dimension will necessarily "tap distinctive constructs". Secondly, citing Gould (1981), he warns that factor analysis does not produce some item of physical reality, but only produces the result of a mathematical exercise. Therefore interpretation of component factors in multidimensional measures can be risky. We need to remember that the concepts we employ in this study of death-related ideas are "human constructions" which do not necessarily give the definitive understanding of the meaning of, for example, death anxiety. However, Neimeyer concedes that when measures of death attitudes are used with due respect and caution, and when used in conjunction with other measures so that comparisons can aid in interpretation of results, many of the existing measures retain their usefulness. These criticisms of death attitude research represent some basis of argument for the use of a more direct and simplified approach (such as that used by Howells et. al., 1986) to asking questions about fear of death.

There may be a range of reasons why death attitudes and death and dying are still accorded relatively little attention in research. There is still some reluctance to talk openly about



and confront issues pertaining to death and dying in our western society. The advances in medical skill and knowledge, which, for example, have made organ transplants possible, perpetuate the search for longevity verging on immortality. Perhaps most important, however, is the difficulty inherent in attempts to research many facets of this human experience. As Kastenbaum (1987-88) suggested, even some researchers find it difficult to confront the issues at a deep level because of their own need to find the balance between approach and avoidance. The very nature of death and bereavement also means that researchers must weigh the benefits of the research against the risks of increasing distress caused to the dying and to the bereaved during data collection processes.

In the difficult area of death attitudes, there is still room for much exploratory work to develop theory and to establish a sound basis for further research. However, thanatological research is still relatively scarce and, like any other area of study, requires time to develop.

### **1.7 - Summary**

The literature on stress in nursing reveals a long list of sources of stress and supports the view that patient death is one of the most important.. There is also an acknowledgement in the literature that sources of stress may vary in importance but levels of self-reported stress tend to be similar across different areas of nursing work. Previous research suggests that patient death, as a stressor, will hold different, and possibly lower, levels of importance for nurses in palliative care than for those in general nursing or psychiatric care.

Further, although it is acknowledged that nursing the dying is stressful and that patient death is a stressful event, and although there have been new approaches to this work, such as holistic care and palliative care, the focus has largely been on the patient. For the benefit of both nurse and patient, it is important to consider whether there are some elements of the nursing experience of patient death which might be modified, to reduce potential for stress for the nurse, without jeopardising standards of care. While previous literature has provided some information about the kinds of deaths which cause stress for nurses, little attention has been given to assessing how the experience of patient death differs across clinical areas.

While there is limited information about fear of death in medical students in the UK, there is no related information about nurses. Although there is a common assumption that all humans fear death to some extent, there has apparently been no research about how nurses' fears would compare with those of members of the general public. Given the role of the nurse and the expectations of what a nurse should deliver in terms of care of the dying, fear of death may influence care given to patients as well as the nurses' ability to cope with the experience of patient death. It is essential that we have an awareness of how nurses' own fears are involved in their work. This is an important gap in the knowledge and understanding of the nursing experience of caring for the dying.

It is recognised that nurses do somehow cope with death and dying and there is an assumption that they cope at some cost, in terms of stress and the negative effects of that stress. There is, however, limited information about whether nurses' perceive themselves to be able to cope with death and dying issues related to work and/or their personal lives. The link between perceived ability and actual ability to do something is well established in psychological theory. An instrument for measurement of perceived competence in dealing with death and dying would be useful in terms of assessing change (in response to training or experience) and assessing differences across nursing groups. Bugen's (1980-1981) work on coping with death and Robbins' (1992) work on death self-efficacy have made a useful start towards development of a measure but more work is required to develop and refine an adequate measure of death-self-efficacy.

The literature acknowledges that there are serious consequences of stress, particularly long-term chronic stress. Burnout is widely accepted as a potential effect of long-term stress, particularly for those who work in demanding human service occupations such as nursing. However, it has also been suggested, in an American study, that one of the effects of caring for the dying can be a phenomenon called 'accumulated loss'. It is contended by Adams et al. (1991) that this phenomenon is specific to those who encounter death very frequently. Burnout, however, is generally accepted to be a response to a broader range of stressors, albeit those generally found in human-service occupations.

The research on accumulated loss phenomenon is very limited and leaves many questions unanswered, about the certainty of the existence of the phenomenon, and about the nature

of the phenomenon. In view of the literature already available on working with the dying, it is a reasonable contention that there may be accumulative effects of this work. However, to support the existence of a particular phenomenon such as 'accumulated loss' requires much more evidence.

### **1.8 - This Research**

This is a study of stress and death attitudes in nurses from three clinical areas of work (palliative, psychiatric and general nursing). The three groups of nurses are appropriate to the study because of the differences in the nature of nursing work in general nursing, palliative and psychiatric care. While patient death can be a part of nursing in any of the three areas, the incidence of patient death varies over the three groups. This allows for comparisons of the effects of clinical experience, different commitments and beliefs and organisational setting on the variables under investigation. The work combines the use of quantitative and qualitative methods and is multi-faceted, with four areas of investigation which, although separate, are closely allied and inter-connected in terms of the nursing role.

The first facet, the investigation of stress as reported in Chapter Four, is intended to provide a contextual background against which the nurses' experience of caring for the dying patient can be studied. The theory of stress and appraisal proposed by Lazarus and Folkman (1984) is used as a guiding conceptual framework in this project and, because the aim is to study group differences, the emphasis is on those commitments, beliefs and situational factors which differ across the groups and which may be important in the appraisal of potential stressors.

The study looks at the experience of stress for this sample of nurses in terms of self-reported psychological well-being and burnout and the importance of sources of stress as perceived and appraised by the three groups of nurses, to determine any group differences and to see how death and dying issues rank in importance with other sources of stress across the sample. Coping strategies are considered, in relation to group differences, reported effectiveness, and those used specifically to deal with patient death.

Uniquely, the second facet, reported and discussed in Chapter Five, addresses fear of death in the nursing sample and compares results with those from a general population sample. It is reasonable to expect that everyone fears death to some extent and that fear of death may increase the stress involved in nurses' work. There is little information available about how nurses' fears are affected by their work or vice versa and there is no previous published work on fear of death in a general population sample from the United Kingdom. This study, building on the previous work, aims to provide further information which could inform death-education and training programmes for health professionals as well as directions for further research in this relatively new area. Additionally, consideration of the levels of fear of death, among those who work with many dying patients and those who rarely experience the death of their patients, may help to answer questions about the effects on nurses of experiencing patient death. This is an important area of study if we are to see nurses' fear of death in proper perspective and understand the relationship between nurses' personal fears and stress related to nursing the dying patient.

Inherent in the nursing role, is the expectation that the nurse will care for the dying in a professional and competent manner and, in some clinical areas such as palliative care, will do so repeatedly throughout a career. The literature suggests that nurses do not always feel adequately prepared to do this work. Previously, in the United Kingdom, there has been no quantitative method of assessing perceived competence to deal with death issues. This study, as reported in Chapter Six, makes progress in this respect by using two relatively new scales from the United States. The work also gathers reliability statistics on the scales and makes some suggestions for further development of a single instrument which would be useful in assessing nurses' perceptions about their coping skills, and the benefits of death education courses. In this third section of the study, using qualitative data, the work also investigates nurses' perceptions about which elements of the experience of caring for the dying patient are responsible for the nurses' appraisal of stress. Without a clear understanding of these elements, there is little hope of making changes which will effectively reduce stress in this area of nursing work.

Finally, it would be an incomplete study without consideration for the effects of the work on nurses, as described in Chapter Seven. This fourth element of the study uses both quantitative and qualitative data to investigate nurses' perceptions of how working with dying patients affects them. Previous literature has given little attention to how the

experience of patient death may differ across clinical areas. The use, in this study, of three samples from distinct clinical areas may improve our understanding in this respect. For hospice nurses who work with many dying patients, it has been claimed that one effect may be 'accumulated loss phenomenon' (Adams et al., 1991). In this very new area of research, this study investigates the credibility of that phenomenon using the quantitative instrument on which Adams et al. based their proposals. In a substantial extension of the original study, data are compared across the three groups of nurses and factor analysis results from the accumulated loss scale are compared with those from the burnout data.

In order to allow the reader clear access to these four large areas of data, each area is reported, with the appropriate discussion, in a separate chapter. The final chapter of the thesis is used to provide an overview of the work and a discussion of practical, theoretical and methodological implications of the findings.

Where the literature has provided a clear direction or conclusion and where quantitative measures can be used to test those conclusions, hypotheses are proposed. However, where the study takes a more exploratory approach because there is insufficient previous research from which to draw conclusions and, where the aim is to report nurses' perceptions, research questions are considered to be more appropriate and are generally, though not exclusively, investigated through the use of qualitative methods. See Chapter Two for more detail.

This study attempts to test the following hypotheses and answer the following research questions:

### **1 The Stress Experience**

**Hypothesis a)** There will be no significant difference across the three groups of nurses on levels of psychological well-being as measured by GHQ-12 or Burnout.

**Hypothesis b)** Appraisals of the importance of a range of stressors will vary as a function of clinical area of work.

**Question a)** Is the stress associated with patient death perceived to be different from other work-related stress?

**Question b)** What are the coping strategies reported by nurses as used and found most effective to deal with work-related stress and, in particular, to deal with patient death?

## **2 Fear of Death**

**Hypothesis a)** Palliative care nurses will have lower levels of fear of death than the other two groups of nurses.

**Hypothesis b)** Scores on Fear of Death will be positively correlated with scores on GHQ-12 (indicating high levels of fear associated with low levels of psychological well-being).

**Hypothesis c)** 'Frequency of patient death experienced' will correlate negatively with levels of fear of death.

**Hypothesis d)** Nurses' levels of fear of death will be lower than those of the general population.

## **3 Coping With Death and Caring for the Dying**

**Hypothesis a)** Palliative care nurses will have higher scores than the other two groups on Coping With Death and on Death Self-Efficacy.

**Hypothesis b)** Scores on Coping with Death and Death Self-Efficacy will be inversely related to scores on Fear of Death.

**Hypothesis c)** Scores on Coping with Death and Death Self-Efficacy will be inversely related to scores on GHQ-12.

**Question a)** Do nurses perceive their training to have been adequate for communicating with and caring for the dying, coping with relatives of the dying and dealing with their own feelings about patient death?

**Question b)** Which elements of caring for the dying and of patient death appear to create the greatest potential for an appraisal of stress and negative effect on the nurse?

## **4 Effects of Caring for the Dying**

**Question a)** What do nurses report to be the effects of caring for the dying?

**Question b)** Is there evidence of the phenomenon which has been called 'accumulated loss phenomenon' (Adams et al., 1991) or is burnout (Maslach and Jackson, 1981) a sufficient concept to explain the symptoms reported by Adams et al.?

## **CHAPTER TWO**

### **Methodology**

#### **2.1 - Introduction**

In a study which aims to investigate stress and death attitudes, there are some important considerations in choosing methods of collecting data. The sensitivity of such subject matter makes observation methods problematic for a non-nurse researcher who might find it difficult to remain sufficiently unobtrusive, either to avoid distressing patients or to collect reliable data. It was, therefore, considered most appropriate to use self-report methods, bearing in mind their strengths and their weaknesses.

Self-reported data are generally collected from oral interview or from written responses to either open-ended or closed-ended questions in questionnaires or diaries/log-books. Data collected in this way provide information, which may be of a qualitative or quantitative kind, directly from the participant. While questionnaires or quantitative measures are useful for gathering large amounts of information from large numbers of subjects, qualitative methods can be more effective for obtaining information about feelings, perceptions of experience and emotional responses to events. An investigation of stress which is related to nursing the dying and to patient death must account for the subjective feelings of individuals if it is to begin to approach an understanding of this experience.

Therefore, a method is required which allows the researcher to gain the detailed richness of data which may be found in the individual's response. This renders quantitative methods inadequate, on their own, to investigate nursing experience and perceptions of patient death. In contrast, the measurement and comparison of concepts such as 'fear of death' or 'perceived ability to cope with death' in different samples require an instrument of measurement which can be used repeatedly, and suggest the appropriateness of a quantitative approach. Therefore, it was decided to use a combination of quantitative and qualitative methods to test the hypotheses and answer the more exploratory research questions. Where possible, the study uses validated pre-existing scales which allow comparison among the samples used in this and other studies.

Denzin (1970) argued that this use of more than one method of gathering information should be the rule in every investigation because no one method can ever account for all of the relevant factors in a situation. Qualitative data can provide a rich source of information on their own. They are also useful to act as a check, confirmatory or otherwise, of conclusions drawn from the quantitative data and provide a way of clarifying or adding detail to a picture being built up from other findings. Likewise, the quantitative results may support or contradict the researcher's interpretation of qualitative data. In this way, the use of both methods allows for 'triangulation', or validation of results of one method through the use of findings from the other (Denzin, 1970; Strauss and Corbin, 1990). While Denzin (1970) proposed that triangulation could apply to the data, the investigator, the theory or the methods, Bryman (1988) placed the emphasis on method.

Cowman (1993) argues that the integration of qualitative and quantitative methods offers a useful response to nurses' concerns that the use of one methodology, in isolation from the other, fails to provide the required understanding of human needs in a nursing context. Vachon (1987) demonstrated the richness of data which could be gathered through interviews and, more recently, the log-book has been shown to be an effective tool (Snape and Cavanagh, 1993). In addition to questionnaires, semi-structured interviews and diaries (similar to log-books) were considered appropriate in this study to address subjective issues related to stress and patient death.

Any research methodology brings with it a range of strengths and weaknesses. It is important to recognise and consider those aspects of any project and to acknowledge whatever limitations they place on the use of findings. Questionnaires used in this study are discussed below, under 'Instruments Used', and are generally instruments for which reliability figures are available. Where the scale is relatively new or without such reliability figures, a part of the work in this study involves assessment and discussion of the reliability of the instrument.

Self-administered questionnaires have the advantage, over interviews, of allowing the respondents anonymity and therefore the freedom to be more candid in their responses to personal or sensitive questions (Breakwell, 1990). This is also true of diaries or log-books which provide a way for informants to record information close to the time of an event,



potentially increasing the accuracy of their data. However, any form of self-report data carries with it the potential for respondent bias or distortion which may result from the subject's desire to present a particular picture of events or make a certain point, or because the subjects are of a particular group whose view of life may differ substantially from that of other groups.

Baillie (1995) makes a point about bias in interviewees in ethnological research which applies to all qualitative approaches. Those participants who volunteer for interview or diary response may have a motivation for doing so which affects the quality, in terms of bias and honesty, of their contribution. Sandelowski (1986) draws attention to the possibility that those who are interviewed may be the most articulate or high-status members of their groups. This is sometimes known as the 'elite bias' and may distort findings if the information is not kept in proper perspective. For example, a sample of nurse managers would not necessarily share the same attitudes as a sample of those nurses who have less experience.

One weakness inherent in the use of interviews is the potential influence of the researcher. The researcher should attempt to create an atmosphere free of bias or judgement and based on trust to encourage the respondent to feel at ease and inclined to give open and honest responses (Breakwell, 1990). The quality of data collected through interviews will be largely dependent on the skill of the interviewer to ask the right questions in the right way to allow free and open comment from the interviewee. It should be remembered, however, that while an interviewer must strive to remain sufficiently neutral to be objective, there is no way of eradicating all influence between two individuals. Thus, the researcher must acknowledge his or her own role in the interaction between researcher and subject (Hammersley and Atkinson, 1983). The assumptions with which s/he undertakes the research, and the part s/he plays in the interview or the effect on the interviewee, of being interviewed, must all be considered.

This raises the additional question of subjectivity in interpretation of data gathered by qualitative methods such as interviews or diaries. Especially in a discipline where quantitative methodology has, until fairly recently, been the more traditional approach to gathering data, there is the possibility that, during the interpretation and presentation of

the data, the researcher may, because of bias, fail to present a true picture and/or may present the data as more representative than it really is (Sandelowski, 1986).

In this study, an attempt has been made to minimize researcher influence and to maintain the required “analytical distance” (Strauss and Corbin, 1990), while using past experience and other knowledge to gather and analyse data collected in this way. Semi-structured, rather than structured, interviews were used because the aim of the interview was to allow and encourage nurses to give their own accounts of their experience rather than to give answers only to specific questions. The non-nurse status of the researcher may be considered a strength in helping to maintain the ‘analytical distance’, in that it allows the researcher to listen and to analyse data, with fewer pre-judgements or assumptions than would likely be held by a nurse.

Establishing rigour, the equivalent of reliability, validity and objectivity (terms which are usually applied to quantitative methodology) in qualitative research is sometimes a controversial and difficult task. Qualitative researchers often feel it is necessary to try to validate their findings by using criteria from the quantitative paradigm (Nolan and Behi, 1995a). However, this is to ignore the major differences between the two paradigms. Guba and Lincoln (1994) propose that the differences between paradigms can be addressed as three kinds of questions which must be answered in a hierarchical manner. That is, the answer to the first will shape the answer to the second and the second answer will shape the third.

These three questions relate to: a) Ontology - the kind of world in which we live, b) Epistemology - the nature of knowledge and the kind of relationship which exists between researcher and subjects, and, c) - Methodological - questions about how knowledge might be generated or discovered (Guba and Lincoln, 1994). One paradigm is based on a positivist philosophy wherein the world is controlled by universal laws which are not influenced by the researcher. What we know is made up of those laws and, in order to gain more knowledge, research controls or manipulates events and/or subjects in an experimental setting (Guba and Lincoln, 1994). Because data are generally in the numeric form, the term quantitative is used but this paradigm is also known as the scientific method (Henwood and Nicolson, 1995).

The other paradigm, known as qualitative, is based on the premise that reality is variable or constructed by individuals in contexts such as race, culture or gender. In this paradigm, the researcher is a part of the process and cannot be totally objective. Therefore, knowledge is a shared understanding and should be gathered by study in natural settings without any attempt to control or manipulate events or subjects. (Guba and Lincoln, 1994).

The distinctions between the quantitative and qualitative paradigms have been the subject of discussion among researchers who believe that there is a less distinct difference. For example, Hammersley (1992) argues that all research, not just qualitative, is based on a set of criteria which evolves from judgement and judgements are subjective. Coffey and Atkinson (1996) argue that researchers on both sides of the 'divide' use both words and numbers as data and that the distinction between the two kinds of data is "more arbitrary than a reflection of major, inherent differences" (p 5). Likewise, there is still controversy about the appropriate criteria for assessment of qualitative research (Nolan and Behi, 1995b). Sandelowski's (1986) work in this regard is considered useful (Hallett, 1995). It is based on four concepts addressed by Guba and Lincoln (1981) which are applied in testing the rigor of conventional scientific research and which are applicable to qualitative work. These concepts are truth value, applicability, consistency and neutrality.

Truth is about discovering the experiences of the participants, as the experience is lived and understood by the individuals. To present the true reflection of the participant's experience and understanding of that experience, the research must be subject-oriented rather than a vehicle to confirm the researcher's pre-conceived ideas or test hypotheses. Thus, it is suggested that 'credibility' is a more appropriate criterion to evaluate qualitative research (Sandelowski, 1986). A study is said to be credible when the presented description or interpretation of the experience under study is recognised by the individual as their own experience. It would also be credible if other people, having only read about such an experience in the study, recognised that experience when it became a reality for them. Hammersley (1992) suggests that the research must present information which is valid and real to some individual. However, he asserts that truth is not absolute but is relevant to the strength of the evidence provided to support any claim or finding of the research. The greater the claims made, the more rigorous the requirements of the evidence. Thus, requirements for truth would differ substantially between research

providing descriptions of events or experiences and that from which new theories or explanations are being raised.

Applicability concerns the usefulness of the findings for generalisation to wider contexts. Sandelowski (1986) argues that qualitative research may be more valid because it emphasises the study of human experience with few controlling conditions, in natural, rather than experimentally controlled, situations. While sample sizes tend to be smaller in qualitative study, this does not necessarily mean that the findings can not be generalised. Notwithstanding the considerations about the nature of informant motivation, mentioned above, and the importance of careful and appropriate weighting to material collected, any person's experience must represent some part of the total experience of the group to which that person belongs (Denzin, 1983). On this basis, no attempt has been made, in this study, to quantify qualitative data from interviews or diaries, because the aim is not to present identical repetition of certain views, but to present a full account of the experiences of the sample of nurses, including variations and/or contradictions.

Consistency or auditability refers to the extent to which a researcher has carried out and reported on a study in such a way that the work may be 'audited' by someone else. Another researcher must be able to understand how conclusions have been drawn and must be able to reach similar or comparable conclusions, given the same data, perspective and situation (Sandelowski, 1986). Hammersley (1992) requires that there be consistency between any claims made and the empirical evidence to support the claims. Thus a written account of the research requires a transparent account of how themes or codes were derived from within the data set as support for any claims made. See 2.3.2 for an account of the process used in this study.

Neutrality or confirmability addresses the issue of bias in the research. The question is really whether the research participants could recognise the reported views and experiences as their own (Hallett, 1995) and whether the researcher's interpretation has been accurate. Hammersley (1992) cautions that the role and impact of the research process and the investigator must be accounted for. In the interests of establishing neutrality in this study, the researcher has adopted a cautious approach to interpretation of data and, especially in the qualitative data, has sought to find and present differing viewpoints which exist within the data.

The difficulties inherent in the process of integrating two different methodologies in research have been underlined by several authors (Oberst, 1993; Breitmayer et al., 1993; Bradley, 1995; Mason, 1994, 1996). Coffey and Atkinson (1996) take the view that “alternative perspectives that are generated by different methods and techniques...do not aggregate toward a complete and rounded picture” (p 14). However, Mason (1996) cautions against any suggestion that it is impossible to integrate research methods but warns that there are both technical and epistemological issues which may arise. She proposes that there are three important questions to answer when considering integration: a) what is the purpose of the integration?, b) how is the integration to be achieved? and c) on what basis can generalizations be made from the findings?

Mason (1996) asserts that the researcher must recognise which parts of the research puzzle can be answered by which method or whether the same questions may be answered at a different level by two different methods. Further, if integration is to be achieved, it is essential that findings from one method are actually related, in some way, to the findings from the other method. If, for example, a quantitative measure addresses stress-levels, will an interview address the same issue or answer questions about sources or effects of stress? Either may be appropriate, as long as the parts of the findings are related and can be integrated into a logical whole which answers the research questions. Finally, Mason queries the basis for generalization of findings, suggesting that conventions for generalizing from quantitative research are better defined and established, leaving qualitative research open to criticism. She proposes that what is vital is that all researchers ask critical questions about the ontological (the view of reality - either controlled by universal law or constructed in contexts) and epistemological (the understanding of knowledge - either the universal laws or a shared understanding) underpinnings of different methods, and the effects of those assumptions on the research findings.

As with Mason (1994), the purpose of using both qualitative and quantitative methods in this study is not solely the use of interview and diary material to validate quantitative findings and vice versa. In this project the qualitative methods were intended to serve both confirmation and completeness, the two intentions inherent in the process of triangulation (Breitmayer et al., 1993). The intention is that the interviews and diaries will provide information which supports/contradicts quantitative findings about, for example, the

importance of stressors and coping strategies but will also “build up a rounded and credible overall picture” (Mason, 1994, p 105), adding detail and possible explanation for some of the quantitative findings, particularly where group differences appear in the quantitative results.

Some areas under study in this project, particularly those related to attitudes to death and dying, are of an exploratory nature and it is acknowledged that a cautious approach to generalization is required and that there is a need for further research. It is also acknowledged that every experience of working with the dying will be unique and every nurse will bring to the experience their own individuality of personality and response to stressors. However, if one nurse finds some element of the experience stressful, that element has the potential to cause stress for other nurses. Further, if that element is one which could be modified, its potential to cause stress to all nurses may be reduced. In this way, some of the qualitative findings in this study, while subjective in nature, may be regarded as valid in wider contexts.

## **2.2 - The Project**

To address the hypotheses and research questions set out in Chapter One, a two-phase study of nursing groups was designed to include self-reporting questionnaires, semi-structured interviews and diaries completed over ten working days. This was combined with a questionnaire survey of a general population sample.

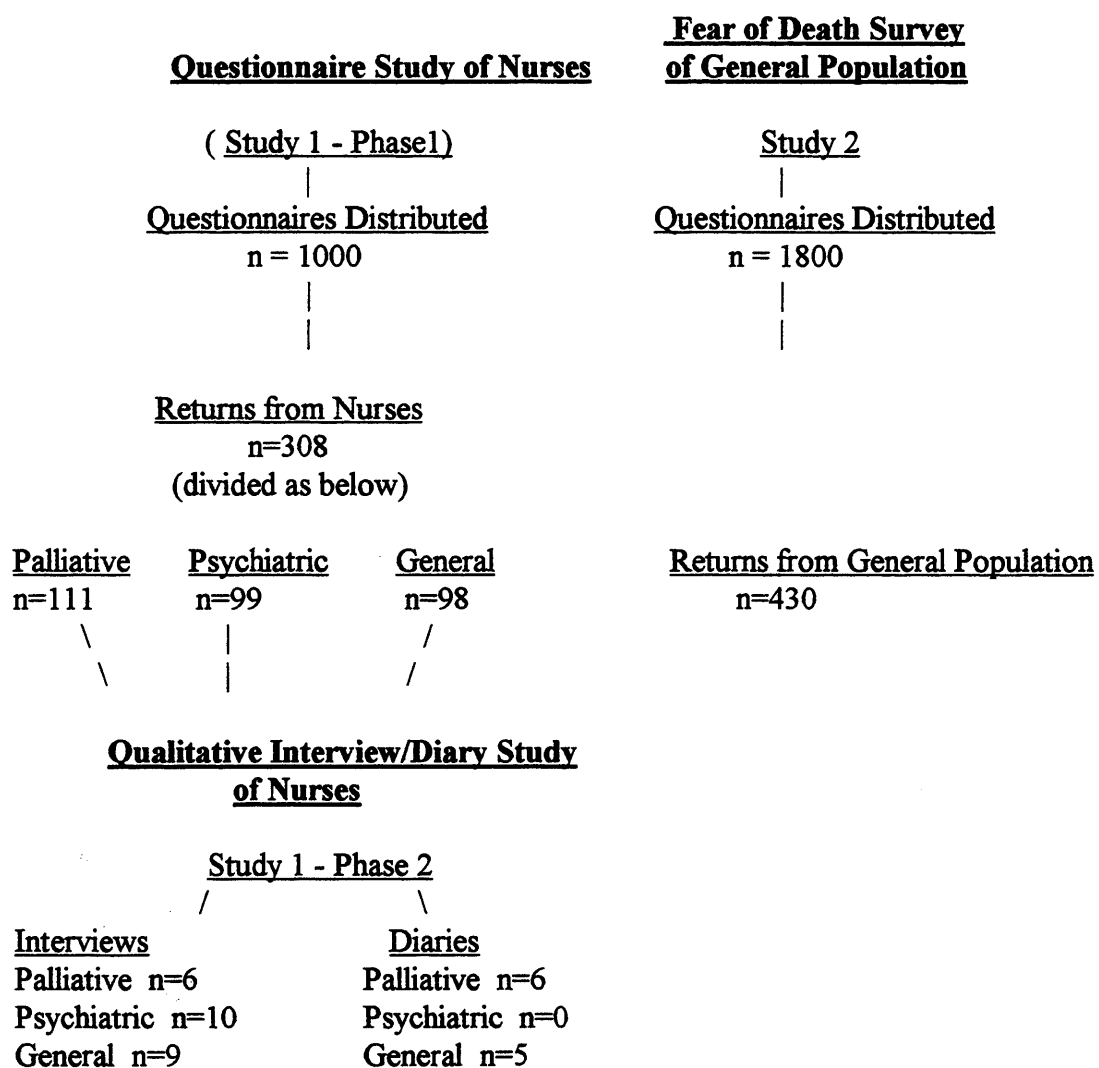
The hypotheses, given above on pages 49-50, were tested through the use of quantitative measures which allowed for statistical analyses of the data. Largely, these questionnaires were standardised and where they had not been widely used previously, reliability statistics were determined in this study. See 2.2.2.iii for information on all quantitative instruments. Where the research was more exploratory, research questions were used (see pages 49-50). These were addressed through interviews, diaries and some open-ended questions on the questionnaires.

On some issues, both qualitative and quantitative methods provided insight. For example, on the question of accumulated loss, the quantitative measure (Adams et al., 1991) provided information from a large sample of nurses, which was compared with results

from the original paper, and interviews/diaries provided individual accounts of the effects of exposure to many patient deaths. In Chapters Four, Five, Six and Seven, details are given of the methods used to address the research issues in each area of study.

The study of nurses will be known as Study 1 (Phase 1 and Phase 2) and the general population survey will be known as Study 2. The following diagram, Figure 1, outlines the course of the work, which includes both studies, carried out between April, 1994 and July 1995.

**Figure 1: THE PROJECT**





### 2.2.1 - Ethical Considerations

Because of the sensitive nature of the topic, several points of ethical consideration were taken into account throughout the project. Access to all nurses was through a managerial route, from the top, down, rather than directly to participants. Permission for the study was granted by the Research Ethics Committee at one of the general hospitals where nurses participated. No other unit or hospital requested any similar clearance.

The anonymity of respondents was considered paramount for the questionnaire and diary portions of the study and assurances of anonymity were included in the questionnaire and diary packages. The researcher wished to encourage honest and full response from nurses and believed this was unlikely to be forthcoming if nurses perceived there to be any risk of information being traceable. There was no way of tracing a particular questionnaire to any nurse and each package contained separate envelopes for the return of notices to volunteer for interviews. Although the researcher knew to whom the diaries were sent, there was no way of knowing the source of a returned document. Verbal assurances of confidentiality were given to all those being interviewed. Verbal permission was gained from each individual for all audio-recording. All respondents were informed that the data were to be used in a PhD thesis, parts of which may be published.

Because of the sensitivity of the subject matter, it was anticipated that some interviewees might be upset by recalling nursing experiences related to patient death. Tissues, tea and coffee were available and whenever there was any sign of distress, the interviewer offered to stop the interview either temporarily or permanently if the subject so wished. Only two nurses became tearful and both expressed the wish to continue with the recording. Both were given time to regain their composure and then continue. Several nurses expressed the opinion that the opportunity to talk to someone who was 'not involved' was beneficial and allowed them to say things which they felt unable to say to colleagues or family.

There was some concern about the ethics of sending the Fear of Death questionnaire to the general public. This concern largely related to the possibility of causing distress to recently bereaved families. This part of the project was discussed with two more experienced psychologists. The consensus of opinion was that the survey was acceptable, especially since the questionnaire contained the researcher's contact address and phone

number, an explanation of why the survey was being carried out and an apology for any distress which might have been caused inadvertently to any recipient of the form.

### 2.2.2 - Study 1 - Phase 1 - Questionnaire Study of Nurses

#### 2.2.2.i - The Sample

Because some of the main aims of the study were to make comparative assessments of fear of death, perceptions of ability to deal with death and dying issues and to investigate the soundness of the concept of 'accumulated loss', it was decided to study nurses from three areas of nursing. Palliative care nurses spend virtually all of their time working with the dying and their training and commitment is to providing the very best in physical and psychological care for the terminally ill. Palliation, rather than cure, is the aim in this field of work. Nurses in more 'general' areas (such as medical, surgical wards or community) care for patients who recover as well as those who are dying. Their training and commitment is more focused on curative measures although some nurses in this group have had training related to care of the dying and their families. Those nurses working in such specialty units as Accident and Emergency and Coronary Care were excluded because of the specialised nature of work in those areas. As a control, psychiatric nurses were included because their experience of patient death is generally less frequent. If nursing experience is a factor in levels of Fear of Death, psychiatric nurses should be different, in this aspect, from palliative care nurses. To limit the complexity of the study, participation was offered only to professionally qualified nurses.

Approximately equal numbers of nurses from several wards or units within each of the three clinical areas were sought. Because this was a voluntary participation study and because the researcher was dependent on nursing managers for distribution within nursing units, the sample was not entirely randomly selected. The effect of this aspect on the data gathered is difficult to quantify.

Access was gained to participating nurses through several different routes. In the first instance, letters were written to local Health Authorities, explaining the purpose of the project and requesting advice on contacting nurses. The Health Authorities responded

with a list of names of nurse managers who should be approached. Letters were sent to the named managers, again setting out the purpose of the project and the need for volunteers. Some managers met with the researcher in person and others replied in writing giving permission in principle and further information about who should be contacted in particular nursing units. Telephone and written contact with this group resulted in managers suggesting other units which may be interested in participation (see Appendix Ia and Ib for sample letters).

Many of the palliative/terminal care nurses were contacted in writing and/or by phone through a network of names which had been gathered during an undergraduate dissertation study (McNeely, 1993). In that study, contact had been established with Macmillan nurses and, through those contacts, other nurses working in hospices and palliative care units were approached. Some additional hospice units were sent letters outlining the project and inviting participation. The London headquarters for Marie Curie nurses (palliative/terminal care) was also contacted with the purpose of finding additional volunteers. The Director was not prepared to give a list of nurses' names but agreed to assist in the distribution of some questionnaires.

#### 2.2.2.ii - Procedure

In all cases, participation in the study was voluntary and, in the questionnaire phase, was on an anonymous basis. Acceptance and completion of the questionnaire (Appendix II) served as agreement to participate. Nurse managers preferred to have the questionnaires left in their possession for distribution within the units. At the two general hospitals, boxes of questionnaires were left with managers who agreed to explain the study to ward Sisters and request that staff be encouraged to participate. 'Drop boxes' were provided for the return of the questionnaire packages to the nursing stations and these boxes were collected from nurse managers by the researcher. The same practice was followed at one of the hospices. This method of collection has been used in other studies (Cross and Fallon, 1985; Tyler and Cushway, 1992). Questionnaires were posted to managers at the other hospice units where distribution method was at the discretion of the managers. Return of these questionnaires was by pre-posted envelope, directly to the researcher. The Director of Nursing at the London headquarters of the Marie Curie nurses was sent pre-paid questionnaire packages, including pre-paid return envelopes and agreed to forward those

to Marie Curie nurses working within an approximate radius of 50 miles of the researcher's base.

Tyler et al. (1991) depended on nursing administration for distribution and collection of their survey, and because of the enthusiasm for this study expressed by most nursing managers, the lack of control over distribution was considered to be an acceptable necessity. This situation gave rise to two concerns. The researcher was unable to determine how individuals or groups of nurses were approached about participation and whether the nature of that approach may have had a substantial effect on rate of participation. Secondly, because the researcher was not able to control distribution, it meant that all questionnaire packages had to be identical. This negated any opportunity to control for the effect of order of testing. Ideally, this might have been done by presenting half of the sample with questionnaires in one order and half of the sample in the opposite order to control for the effect of one test on another. However, since every respondent received the same package, any effect of the order of testing would likely apply to all participants. Therefore, the overall effect should not make comparisons of the data from the three groups of nurses any less reliable.

In total, 1000 identical packages were distributed among nurses from the three areas (Palliative - 330, Psychiatric - 270 and General - 400). The differences in numbers for each clinical area resulted from the different policies adopted by nurse managers. Some checked, verbally, with their staff to get approximate numbers of nurses who showed interest before agreeing on a number of questionnaires which they should receive. Other managers simply asked for a number which approximated the number of staff in their units.

Each package contained a series of questionnaires (listed and explained below, copies in Appendix IIa to IIj inclusive) with instructions for completion, assurances of confidentiality, the name and contact number of the researcher, a form on which the respondent could volunteer to be interviewed at a later stage (Phase 2), and self-addressed, prepaid return envelopes for returning the questionnaire and the interview form separately to insure anonymity for the questionnaire phase. This resulted in 308 useable returns, a return rate of 31 percent overall (Palliative - 34%, Psychiatric - 37%, General - 25%). A questionnaire was rejected if more than one scale had not been answered. Some missing values were allowed and coded as such.

### 2.2.2.iii - The Instruments Used

1. *A purpose designed questionnaire* containing questions about age, gender, hours worked per week, area of work and other demographics. This instrument also included questions about specialist training which nurses had received, main perceived effects of patient death, coping strategies used to deal with stress and with patient death and which of those were considered to be most effective. See Appendix IIb.
  
2. *A purpose-designed questionnaire*, listing 24 potential sources of work-related stress and asking respondents to rate their feelings about those aspects of their work. The list was compiled from the findings of other published studies (Tyler et al., 1991; Cooper and Mitchell, 1990) as well as information gathered in a previous unpublished study (McNeely, 1993). Ratings were from 1 to 5 under the headings 'not stressful', 'only occasionally stressful', 'somewhat stressful', 'quite stressful' and 'extremely stressful'. The first category, 'not stressful', allowed the respondent to make a positive statement that this was not a source of stress. The remaining four categories allowed a grading of the importance of each potential source of stress. 'Stressful' was defined as "causing you worry, making you feel pressured or anxious". Respondents were invited to list and rate any other aspect of their work which was not on the list but which they found particularly stressful. See Appendix IIc.

Realistically, it is important to acknowledge the difficulties of measuring subjective ideas or feelings. The complexity and individuality of the stress process have already been discussed in Chapter 1. Sources of stress may differ in importance from one day to the next with any individual nurse. Further, the meaning of terms such as 'quite' or 'extremely' may differ among individuals. The researcher was also aware of the potential implications of two factors which were relevant to the nursing culture as a whole, and more specifically, to some units at or around the time of the study. Nurses were involved in pay negotiations with the government and the media carried many stories of nurses feeling aggrieved at their treatment in this regard. Some of the units involved in the study had been through a period of change to Trust status, an experience which had much potential for causing stress. It was decided that if these factors were to bias nurses' replies

unduly, it would be a very visible and legitimate result, in that they would state those things as the important sources of stress.

It must be acknowledged, therefore, that any rating of importance of sources of stress can only be seen within the context in terms of sample, time and situation of a particular study. In this study, the ratings are meant to help to provide the background picture of stress among nurses, against which the relative importance of patient death and the nursing experience of caring for the dying may be more clearly seen.

3. *The 12-item General Health Questionnaire (GHQ-12, Goldberg, 1972, Goldberg and Williams, 1988)*, Appendix II.d. This instrument focuses on psychological components of ill-health and is aimed at detecting psychiatric disorders which may be relevant to attendance at a medical clinic. It is recommended by Banks et al. (1980) as a suitable instrument "for comparing levels of psychiatric illness within and between populations. Used in this way the GHQ provides a useful estimate of the severity of psychiatric illness for use in the study of employment-related and occupational problem." (Banks et al., 1980, p 193). Using the GHQ-28, Tyler et al.(1991) and Tyler and Cushway (1992) demonstrated the usefulness of the scale to measure negative mental health outcomes related to workplace stress among nurses. In this study, the GHQ-12 is preferred because of the overall length of the questionnaire package and is used to compare scores among the three groups of nurses.

Banks et al. (1980) confirm the adequacy of the psychometric properties of this scale, reporting item-whole correlations of 0.47 or higher and Cronbach Alpha coefficients of 0.80 or higher throughout their studies. Vieweg and Hedlund (1983) also support the validity of the GHQ-12, quoting validity statistics in excess of .80 in a range of other studies. The 'Likert-method' of scoring responses was used in this study (ie 0,1,2,3) and is recommended by Banks et al. (1980) where parametric tests are to be used. However, since the data lacked normal distribution, thereby making parametric tests inappropriate, data were recoded using the GHQ method of 0-0-1-1, to assess the number of cases over the threshold of 2/3 which was recommended in the GHQ Manual (Goldberg and Williams, 1988, 1991).

4. *Maslach Burnout Inventory (MBI)*, (Maslach and Jackson, 1981), Appendix IIe. This instrument is compiled of three subscales which assess the three aspects of the phenomenon which has been called burnout by Maslach and Jackson. These aspects are emotional exhaustion (EE), depersonalisation (DP) and lack of personal accomplishment (PA). Burnout is not a dichotomous variable, but rather, is measured on a continuum which indicates low, moderate or high degrees of burnout. High burnout is said to be indicated by high scores on emotional exhaustion and depersonalisation and low scores on personal accomplishment. Moderate burnout would be reflected in moderate scores on all three sub-scales and low burnout would be indicated by low scores on emotional exhaustion and depersonalisation and high scores on personal accomplishment.

The authorised manual for the MBI states that scores on the sub-scales are considered to be high if they fall into the upper third of the normative distribution, average if they fall into the middle third and low if they are in the lower third. Table 2.1 shows the categorisation of scores for medical workers which includes nurses, as well as the means and standard deviations for this group (Maslach and Jackson, 1986, p 3 and 9).

Table 2.1: Categorisation of scores on MBI for Medical workers (Maslach and Jackson, 1986, p 3,9).

| Medical workers (n=1104)  | Emotional Exhaustion | Depersonalisation | Personal Accomplishment |
|---------------------------|----------------------|-------------------|-------------------------|
| Categorisation of scores: |                      |                   |                         |
| Low                       | ≤18                  | ≤ 5               | ≥ 40                    |
| Average                   | 19 - 26              | 6 - 9             | 39 - 34                 |
| High                      | ≥ 27                 | ≥ 10              | ≤ 33                    |
| Mean                      | 22.19                | 7.12              | 36.53                   |
| SD (standard deviation)   | 9.53                 | 5.22              | 7.34                    |

Reliability coefficients (estimated by Cronbach's Alpha coefficient) are given by Maslach and Jackson (1981) as EE=0.90, DP=0.79 and PA=0.71 with standard error of measurement for the subscales as EE=3.80, DP=3.16 and PA=3.73. No test-retest reliability figures are given for the medical worker group but coefficients significant beyond the 0.001 level are given for social welfare graduates and health agency administrators on test-retest over 2 to 4 week periods. Claims for the validity of the instrument are based on a range of research by Maslach and colleagues which is reviewed in the Manual. MBI scores were correlated with behaviour ratings made by an independent person who knew the respondent well, the presence of job characteristics which were considered to be contributors to burnout (eg heavy caseloads) and with

personal outcomes which were believed to be related to burnout (eg dissatisfaction with opportunities for growth and development in the job).

The manual states that, to demonstrate that burnout is a separate construct not to be confounded with job dissatisfaction, measures of job satisfaction were correlated with MBI scores and found to be moderately negatively correlated with emotional exhaustion and depersonalisation and moderately positively correlated with personal accomplishment.

The MBI was developed on the basis of research with samples from medical workers (n=1104), which included nurses and doctors. Further, the concept of burnout as a consequence of chronic stress is said to be particularly relevant in human-service occupations (Maslach and Jackson, 1981) which renders this scale appropriate to nursing studies.

No missing values are allowed on the MBI (Maslach and Jackson, 1986), so only fully completed MBI questionnaires were considered useable in this study.

5. *The Fear of Death Scale (FOD)* (Howells, Gould and Field, 1986), Appendix IIf, was used to assess levels of fear and frequency of thinking about death and dying. Questions in the scale relate to the thought of one's own dying, being dead, the death of someone close and talking to a dying patient about their condition. Responses are ratings on Likert-type scales. Levels of fear were measured from 1 to 7 with 1 being 'not fearful at all' and 7 being 'extremely fearful'. Frequency of thought was measured on 1 to 5 ratings with 1 being 'very rarely' and 5 being 'almost every day'.

Reliability and validity studies were carried out on the first three questions of this scale by Howells and Field (1982). Investigation including test-retest correlations, and correlation with a more complex measure of fear of death (the Collett-Lester Scale, 1969) led Howells and Field to conclude that these questions had high face validity, were reasonably reliable over time and showed significant correlation with the more complex measure (Howells and Field, 1982). No such information is available on the remaining FOD questions as used in this study. Questions which relate to the frequency of thought about aspects of death and dying may be particularly suspect. Anecdotal evidence suggests that responses to these questions would be highly susceptible to individual experience near the time of



questioning. In this study, information from these latter questions was used only to assess nursing group differences.

6. *The Coping with Death Scale (Bugen, 1980-1981)*, Appendix IIg. This instrument was designed to measure changes in specific competencies which hospice volunteers might display after participating in a program of death education. One might expect that professionally qualified nurses would feel relatively competent to deal with issues with which hospice volunteers are expected to cope and therefore should, overall, score highly on this scale. In this study the measure is being used as a comparative measure to assess group differences in perceived abilities to cope with death related issues. The 30-item scale requests respondents to agree/disagree with statements. The amount of dis/agreement is rated on a Likert-type scale of 1 to 7 where 1 is 'do not agree at all', 4 is 'neutral' and 7 is 'agree completely'. Scores are obtained by reversing items 13 and 24 and then using the total score. Robbins (1991) reports internal consistency ratings of  $\alpha=0.89$ ,  $p < 0.001$  and test-retest stability ratings, over a two-week period with a sample of students (n94), of  $r = 0.91$ ,  $p < 0.001$  for this scale.

7. *The Death Self-Efficacy Scale (Robbins, 1992)*, Appendix IIh. Based on Bandura's social learning theory, Robbins has developed this scale to assess those competencies which would be required in hospice work as well as perceived self-efficacy in coping with personal bereavements and death-preparation behaviour. Scoring of 0 to 10 (highly uncertain to completely certain) is used on this instrument where respondents are requested to say how certain they feel that they could perform particular tasks. The scale has not been widely used but Robbins reports internal consistency ( $\alpha = 0.94$ ,  $p < 0.001$ ), using a sample of 320 volunteer workers from hospital and hospice settings. Test-retest stability was measured with a sample of undergraduate students (n=39) over a 2-week period ( $r = 0.91$ ,  $p < 0.001$ ) (Robbins, 1994).

This scale has been used alongside the Bugen scale for two reasons. Firstly, the scale is used as a comparative measure to assess group differences in perceived death self-efficacy and secondly, using both makes it possible to assess the necessity for two separate scales (using factor analysis and correlation).

8. *Accumulated Loss Phenomenon Questionnaire (ALP, Adams, Hershatter and Moritz, 1991)*, Appendix III. This instrument is a lengthy questionnaire which was used to gather information from 100 hospice care-givers, including nurses, in an American study. The findings led the researchers to propose that there is a specific phenomenon (ALP) from which hospice care-givers may suffer. Their proposal was based on the results of a 5-Factor Varimax rotation which "revealed five basic characteristics of accumulated loss" (Adams et al., 1991, p 30). No information has been forthcoming from the authors of the paper regarding the methodological details of analysis used in their study. For example, there is no information about the normality of distribution of their data, number of items used in the factor analysis or factor loadings.

This questionnaire is used in this study for three reasons. First, there has been only limited work done to establish the existence of ALP. There is not yet conclusive evidence that the phenomenon exists, and this question can only be answered by gathering more information. At this stage, it seems appropriate to do so by using the same questionnaire as Adams et al., rather than cloud the issue with a different set of questions. Secondly, since this is a comparative study, group differences may help to clarify whether, if ALP exists, it is related to one specific area of nursing. Finally, the study also includes the Maslach Burnout Inventory and information from the ALP questionnaire can be compared with the MBI scores to see what support, if any, exists for the idea that ALP is a "set of unique characteristics by which care-givers develop certain behaviours, both positive and negative" (Adams et al., 1990, p 30). A high level of correlation between scores on some of the ALP items and the MBI scores would suggest that ALP may simply be burnout among hospice care-givers.

9. *A supplemental page*, Appendix IIj, was included inviting nurses to write about losses at work, other than death-related ones, main frustration at work, and least and most rewarding aspects of work. Answers from these questions were coded numerically and entered into computer analysis to obtain frequency data. Appendix IIj also shows two questions regarding social support which were included in the questionnaire.

Wherever modifications have been made to any of the above instruments, they have been of a minor nature relating to syntax rather than construct. One example of a change is the substitution of the word 'unit' for the word 'hospice' where necessary to make the

question applicable to all respondents from the three nursing groups. There is no reason to believe that any of the changes would alter the meaning of the question.

To summarize, the instruments for Study 1, Phase 1, found in Appendix IIa to IIj inclusive, were a purpose-designed questionnaire about demographics, specialist training, effects of patient death and coping strategies, a purpose-designed questionnaire about sources of stress, the 12-item version of the General Health Questionnaire, the Maslach Burnout Inventory, the Fear of Death Scale, the Coping With Death Scale, the Death Self-Efficacy Scale, the Accumulated Loss Phenomenon Questionnaire and some open-ended questions about work-related losses other than patient death, main frustrations at work and least and most rewarding aspects of work.

### 2.2.3 - Study 1- Phase 2 - Interview/Diary Study of Nurses

#### 2.2.3.i - The Sample

Respondents who, during Phase 1- the quantitative study, volunteered to be interviewed at a later date, gave names, addresses, contact numbers or addresses and instructions about how the researcher should gain permission for access from employers if the respondent wished to be interviewed at their place of work. These volunteers were re-contacted by post and those who were still willing to participate were either invited to an interview or invited to complete a ten-day diary (Appendix V) about stress and patient death at work.

#### 2.2.3.ii - Procedure

Semi-structured interviews and diaries were completed over a three month period and approximately ten to thirteen months after nurses completed the questionnaires. Figure 1, shown above, shows that qualitative data were gathered from approximately equal numbers of nurses from the three groups.

Semi-structured interviews were considered appropriate in order to allow the researcher to keep the interview topic focused, but at the same time to allow sufficient flexibility to take advantage of the varied nursing experience within the sample and where appropriate to put greater emphasis on some specific aspects of the research. Of necessity, there was some

variation in the settings in which these interviews were carried out. A few nurses requested that the researcher see them at their place of work and some were interviewed in their homes. One nurse was interviewed at the home of the researcher and the remainder were interviewed at college offices. In all cases only the interviewer and the interviewee were present and the attempt was made to have an informal and relaxed atmosphere.

Each interview was audio-recorded with the permission of the interviewee. This allowed the interviewer to give full attention to the respondent without the necessity of taking notes. It also allowed the information to be transcribed where necessary and provided the opportunity to listen to the interview at a later date and as often as required. There was little evidence of the recording process affecting the interview progress. The only visible sign of this effect was that some respondents looked at the recorder rather than at the interviewer when answering the first few answers. However, any effect which was apparent disappeared after the first few minutes of the session and interviewees generally appeared to be at ease.

### 2.2.3.iii - The Instruments

Phase two consisted of semi-structured interviews (n=25) and diaries (n=11). Nurses completed either interview or diary but not both, and were volunteers from those nurses who completed Phase One.

Interviews were guided by a set of questions (see Appendix IV ). These questions were devised to allow the respondent to talk openly about stress at work, dealing with patient death, and the effects of work on their personal lives. The intention was to gather information which reflected the feelings, perceptions and experiences of the interviewee. There was no intention to answer a very specific set of questions but, rather, to gather an understanding of nursing experience from nurses' own accounts of that experience. Thus, the questions were largely open-ended and the interview semi-structured, allowing flexibility to gather the information relevant to each individual's experience.

The interview schedule was devised to include questions focusing on stress at work, patient death and coping. An overall aim of the interviews was to determine which elements of the experience of patient death were perceived to cause stress, or, using the

framework of Lazarus and Folkman (1984), caused the nurse to make an appraisal of stress in the event of patient death. Although previous literature and the quantitative part of this research had shown that patient death was considered, by nurses, to be very important as a stressor, the interviewer attempted to avoid the assumption that every interviewee would perceive that to be the case. Therefore, the question 'What are the major emotional issues which you face in your work?' was intended to allow the respondent to give his/her own order of importance to emotional stressors. This allowed the interviewee to mention other emotional issues and, when patient death was one of the responses, the interviewer was able to focus on that issue. Generally, however, the interview schedule was used only as a guide for the interviewer to remain focused on the areas under study.

Diaries (see Appendix V) were based on the work of Cavanagh and Snape (1993) who used log-books and, again, focused on stressful incidents and patient death. The use of diaries allows respondents to record appropriate information on a daily basis, over an extended period of time, rather than on a single day when being interviewed. This should increase accuracy of the report since it is written soon after the event. It also allows the nurse to write about feelings, perceptions, appraisals and events without the influence of an interviewer. In this project, diaries provided, for the nurses, a choice of method of participation in the second phase. Feedback from the 'open comment' section of the diaries informs that some of the nurses who completed diaries found it a therapeutic exercise. For the researcher, diaries provided a third method of data-collection which assisted in the triangulation processes (Bradley, 1995). Diaries also provided a cost-effective and convenient way of gathering data from some nurses who were prepared to give information but who lived a considerable distance away from the researcher's base.

The diaries were printed documents sent, by post, to nurses, and designed to cover ten working days. A total of 16 diaries were posted with a return of 11 (69 percent). Although five diaries were posted to psychiatric nurses, none were returned and it is impossible to know the reason for this. Questions for each day related to the most stressful incidents at work and their effect on the nurse and any experience of patient death during those ten days. Respondents were also invited to make open comments.

Although diaries and interviews share the qualitative approach to data collection, of necessity in this study, they differ in the amount of information which could be gathered. In light of the feedback from the quantitative study about nurses' concerns about an excess of paperwork and research questionnaires with which they had to contend, the researcher gave considerable thought to diary design. In order to encourage completion and return, the attempt was made to keep questions concise and limited in number while giving an opportunity for any respondent to make as much free and open comment as they wished.

#### 2.2.4 - Study 2 - Fear of Death Survey of General Population

##### 2.2.4.i - The Sample

The sample for the General Population Survey consisted of members of the households in a small Midlands market town. The town comprises a small business section, primary and middle schools, two surgeries for doctors and a dentist, and a small industrial estate. Residential sections include a mix of larger 'executive homes', several housing estates of family homes, council estates of both family homes and bungalows for the elderly and different types of older homes dating from 50 to 100 or more years ago.

The town was chosen because it presented a unit which was manageable in terms of distribution of questionnaires. Royal Mail was to deliver the survey envelopes. Two patterns of delivery were considered. The envelopes could be delivered to every household in the town or they could be delivered in some randomized method to a given number of households within a larger area. In either case, the researcher was dependent on postal workers to deliver correctly, according to whichever method was chosen. It was decided that the first method was more likely to be correctly carried out and that the town was a suitable size to be treated as a unit.

One criticism of the use of this particular town may be that it contains a predominantly white, anglo-saxon population with only very minimal representation of ethnic groups. However, this may be seen as an advantage, insofar as there is little opportunity for ethnic differences to be a confounding variable in the measurement of attitudes to death. Ethnic differences were not investigated within this study.

Characteristics of the sample, in terms of age, gender and socio-economic groupings are discussed in Chapter Three and compared with the 1991 Census figures for the East Midlands region.

#### 2.2.4.ii - Procedure

The Royal Mail Door-to-Door service was used to distribute a survey package to every household (1850) in the town. The instructions requested that only one person, 18 years of age or older, from each household should respond. 430 completed questionnaires were returned, a rate of 23 percent. In view of the subject matter under investigation, this was considered a reasonable return rate for a postal survey.

#### 2.2.4.iii - The Instrument

The purpose of this study was to gather data from a sample of the general population on fear of death scores, using the same questionnaire measure as was used with the nursing sample (Fear of Death Scale, Howells, Gould and Field, 1986). The questions related to patient death were excluded from this questionnaire. This survey was required to provide a base-line against which the nursing scores on the other three questions could be measured.

It is acknowledged that, while the aim is to survey a cross section of the general population, a postal survey pertaining to fear of death may draw response from a biased segment of that population. It is possible that only those with lower fears may feel confident enough to reply. However, the conditions of response, anonymity and voluntary participation apply to both nursing and general population samples. There is no way of knowing what biases may affect samples and, in voluntary participation-studies, there is no way of eradicating the potential for bias. Therefore, acknowledging the limitations of data collected in this way, it was considered acceptable to compare the data from the two surveys (nursing samples and general population sample).

Each envelope delivered to a household contained a self-addressed stamped return envelope and a single-sheet document which gave an explanation of what the study was about and directions about who was to complete the questionnaire part of the document. Questions about age, gender, occupation of the 'head of household' and recent

bereavement were asked along with six questions from the Fear of Death scale (Howells, Gould and Field 1986). All six questions on this scale were measured by a Likert scale of 1 to 7. See Appendix III.

## **2.3 - Data Analyses**

### **2.3.1 - Quantitative Data Analysis**

The 'SPSS for Windows' computer software package was used for all of the analyses of the quantitative data. Nonparametric statistical tests were used because scores on many of the scales did not satisfy a normal distribution. Siegel (1956) believes that nonparametric tests are particularly appropriate for behavioural science research. These tests are not dependent on normal distribution of the sample from which data is collected. Further, nonparametric tests often work with ranks rather than actual scores and, in Siegel's opinion, this makes them more suited to research of subjective ideas, such as attitudes, where numerical scores may not represent precise values.

Siegel (1956) explains that, generally, the strength of any conclusions reached from test results will be dependent, in part, on the strength and extent of the assumptions underlying the test. This would suggest that nonparametric tests are less powerful in terms of rejecting the null hypothesis when it is false. However, some nonparametric tests are very powerful. For example, the Kruskal-Wallis one-way analysis of variance, a test of differences among several independent samples, is considered to have almost the same power as the  $F$  test, which is the strongest parametric test. Further, where sample sizes are much larger than twenty, nonparametric tests can be used, yet retaining power to reject the null hypothesis when it is false. This is because increasing the sample size increases the power of any nonparametric test (Siegel, 1956). Therefore, while it is desirable to use parametric tests wherever the assumptions can be met, nonparametric tests are preferable alternatives when using data which do not present normal distribution patterns and where sample sizes are relatively large.

While parametric analyses can clearly be justified, there has also been a tradition of using Factor Analysis to explore the relationships between the variables in attitude rating scales (Kline, 1994). In this study, the failure of the data to demonstrate normal distribution



patterns raised a query about the intention to use exploratory factor analyses of some of the data.

Spearman (1904) originally developed factor analysis for the purpose of exploring a field of data to determine the underlying constructs (Kline, 1994). In this test, variables which correlate with each other but are largely independent of other variables are grouped into factors (Tabachnic and Fidell, 1989). Factors are hypothetical constructs, rather than real variables. These hypothetical constructs represent shared variance amongst a group of correlated variables and thereby help to explain the overall idea which is common to that group of variables (Polit, 1996). Factor loadings are the numerical correlation of a variable with the factor. Thus there may be ten variables correlated with a factor and each variable will have a loading which describes the extent to which it correlates with the factor. When the factor is examined for content, it may be possible to describe the variables, particularly those which are highly correlated with the factor, under one heading or construct (for example, weight, height and foot size could be described as physical characteristics). In this way, factor analysis simplifies large amounts of data.

If the intended use of factor analysis is inferential, an assumption underlying the use of this technique would be the normal distribution of data. However, Tabachnic and Fidell (1989, p603) state that “as long as PCA (principal components analysis) and FA (factor analysis) are used descriptively as convenient ways to summarize the relationships in a large set of variables, assumptions regarding the distributions of the variables are not in force.” Normality of distribution would enhance any solution but, even when this is not the case, the solution may be useful (Polit, 1996). For the purposes of this study, the intended use of factor analysis is descriptive insofar as, for each of the scales, a summary is required of relationships between variables. Factor analysis may thus be considered to provide an effective method of determining those relationships. See Chapters Six and Seven.

Characteristics of the sample under study will obviously have an effect on the reliability of factor analysis results. In particular, the size of the sample, the presence of homogeneous sub-samples within the sample, and the ratings used on the questionnaire are of interest. Sample sizes should generally be between 100 and 200 and at least five times as large as the number of variables or scale items (Polit, 1996). If the sample contains homogeneous sub-samples (which may be males and females or, in this study, could be groups based on

different kinds of nursing work), the result of the factor analysis is likely to be affected by differences which relate to the groups. This is because the correlations between variables may differ from group to group (Howell, 1992). Where there is a restricted range of ratings allowed for response to questionnaires, the correlations between variables may be different from what would be found with a wider range of ratings. The effect which is most often found is that the correlations will be reduced (Howell, 1992). If this happens, the result will be a correlation matrix with low correlations which may make factor analysis inappropriate.

### 2.3.2 - Qualitative Data Analysis

Just as there are many different kinds of data, so there is a variety of approaches to analysing qualitative data. Underlying these approaches is the concept of “transforming and interpreting qualitative data..... to capture the complexities of the social worlds we seek to understand” (Coffey and Atkinson, 1996, p 3). The same authors suggest that there is no “right or most appropriate way to analyze qualitative data” (p6) and that there are different views of what analysis means.

Wolcott (1994) contends that, under an umbrella term of ‘transformation’, description, analysis and interpretation are three ways of dealing with qualitative data. Description is a process of telling whatever story is in the data in a descriptive way, but staying very close to the data. Analysis, in this context, is a structured, systematic, controlled and documented procedure of identifying elements and relationships within the data. In a process of interpretation, the researcher goes beyond the analysis, to offer his or her own interpretation or explanation of what is happening in the data. These are similar to processes described by Huberman and Miles (1994). The major difference, however, is that Wolcott argues that transformation of data may employ one or a combination of the three processes.

In this study, the qualitative work combines the descriptive and analytic processes, insofar as the intention is to report what nurses say and to determine the relationships among some of the factors in those data. While patterns may emerge from the data, it is not a universal pattern which is sought (as, for example, in a full analytic induction or grounded theory analysis). Rather, the aim is to report the diversity of nurses’ perceptions of the

experience of caring for dying patients. To reiterate, any person's experience must represent some part of the total experience of the group to which that person belongs (Denzin, 1983). Further, any part of the experience which causes stress for one nurse has the potential to cause stress for other nurses. Therefore, to present only those experiences which appear to be universally stressful would be to present an incomplete picture of the phenomenon under study.

While the quantitative study provides considerable information about groups of nurses and statistical measurement of some attitudes and perceptions, the qualitative study is meant to illuminate those findings, adding completeness to the story, by focusing on the individual perceptions and appraisals of threat or challenge, as expressed in Lazarus and Folkman's (1984) model of stress. In addition, the qualitative data tell a story on their own about what causes nurses to appraise stress in a situation surrounding patient death.

The taped recordings of the first four interviews were fully transcribed and the transcriptions analysed to determine whether the interviews were gathering the required information and were being kept sufficiently focused. For the remainder of the analysis, all tapes from interviews were listened to and transcriptions made, editing out material which was considered irrelevant to the study. The interview and diary sections of the study were specifically intended to address the following issues:

Hypothesis 1b) Appraisals of the importance of a range of stressors will vary as a function of clinical area of work - note that while this hypothesis is tested through a quantitative measure, the qualitative data are intended to add clarity, either supporting or refuting quantitative findings or providing some explanations of why there may be group differences in reported stressors.

Question 1a) Is the stress associated with patient death perceived to be different from other work-related stress?

Question 1b) What are the coping strategies reported by nurses as used, and found most effective, to deal with work-related stress and in particular, to deal with patient death? Note that this question was addressed through the questionnaire, from which the data was treated quantitatively but, again, the qualitative data is intended to add clarity or explanation.

Question 3b) Which elements of caring for the dying and of patient death create the greatest potential for an appraisal of stress or negative effect on the nurse?

Question 4a) What do nurses report to be the effects of working with the dying?

Using a procedure similar to the template method (Crabtree and Miller, 1992) which uses codes or themes devised prior to data collection, the broad themes of 'stress and its effects', 'coping', and 'death and dying' were applied during this editing process. All information within the data which could add, in any way, to an understanding of those broad themes was transcribed. Tapes were listened to at least twice and sometimes, in part, several times in order to check for accuracy of transcribed quotations, to confirm or clarify meanings by checking the context, to assess the relative importance of items of data and to look for contradiction or differing viewpoints.

Transcriptions were then read to draw out other sub-categories. For example, the broad heading of 'stress and its effects' was sub-divided into the 'sources of stress' and 'effects of stress'. 'Coping' was divided into 'strategies' and 'negotiation of support' which became an obvious category because of the reported importance of social support. Study of the data under the broad heading of 'death and dying' resulted in several sub-categories.

It was decided that a useful framework within which to organise the data which specifically focused on patient death would be based on timing of events, similar to Parkes (1986, 1996), so the data items were listed separately, under three categories of 'what happens prior to death', 'the event of patient death' and 'what happens after the patient death'. The data under each of those categories were further analysed to assess what elements of the three categories may be significant in increasing or decreasing the negative effects on the nurse. During analysis, items of information were coded using +, -, and 'pos' to signify respectively, 'stressful', 'less or not stressful' and 'a source of some positive reward' as reactions to any part of the experience.

Using a process similar to analytic induction (Bryman and Burgess, 1994), the researcher, having become familiar with the data, formulated a hypothesis or explanation and then continued the search through the data set to see whether the explanation was correct or was contradicted. For example, data from several nurses indicated that missing the actual death of one of their patients was traumatic to some degree, because of a heightened sense

of loss, feelings of letting the patient down and feelings of unfinished business. After further exploration of the data, it was apparent that for some nurses, missing the death could bring a sense of relief. In the interests of presenting a balanced picture of the evidence gathered, the analysis of all qualitative data included a specific effort to find and present information which illustrated different viewpoints or a view which contradicted the dominant picture. It is only in this way that a comprehensive account of the nursing experience of this sample can be given.

The above procedure of analysis excluded the final steps in analytic induction which require a continuing analysis of data and redefinition and reformulation of phenomena and hypotheses until there are no cases within the data which contradict the researcher's hypothesis (Bryman and Burgess, 1994). This constitutes a search for a universal pattern. To reiterate, in this study, it is not a universal pattern which is sought. Rather, the aim is to present the subjective range of nurses' perceptions of the experience of caring for dying patients.

Wherever reference is made to data from interviews or diaries, this is indicated by the interview number (INT...) or diary number (D...) and where appropriate, by an indication of the nursing group of which the respondent is a member (PALL = palliative, PSY - psychiatric or GEN = general). Where nurses are engaged in two kinds of work (usually palliative care combined with one of the other two), this is indicated. A single reference or quotation does not necessarily indicate that this is the only example of a particular experience or point of view within the data.

### Diaries

The same categories of 'stress and its effects', 'coping' and 'death and dying' were used to sort data from the diaries. As the data were explored, items which were relevant to categories and sub-categories, devised from interview data, were listed and marked as sourced from diaries. Although the diary questions are slightly different from those in the interview schedule, the focus of the diary was still on stressful events, effects of stress and patient death and the data from diaries was considered to be an addition to interview material, rather than distinctly separate.

### 2.3.3 - Integration of Findings

The integration of the findings from the two kinds of investigation (quantitative and qualitative) followed a question and answer approach. The two sets of data were analysed separately and conclusions drawn from the two sets of findings. The more descriptive role of the qualitative work resulted in the reported elements of the experience of nursing the dying patient (see Chapter Six). Then, in response to conclusions from the quantitative data, the qualitative findings were 'trawled' for any possible support or contradiction or explanations which would assist in the understanding and answers to the research questions. For example: quantitative data showed differences of importance of stressors across the three groups of nurses - the interview and diary data were explored to see whether interviewees from different clinical areas had provided any possible explanations for these differences; the quantitative data showed that social support was a most important coping strategy - the qualitative data provided information about how nurses negotiated that support. Similarly, when there appeared to be a particular conclusion from the qualitative data, based on small numbers of nurses, the quantitative findings were considered to see whether the same conclusion could be drawn from the data from the larger sample. As the researcher became increasingly familiar with the data, questions such as 'What other influences may be involved here?' or 'How does this finding relate to another finding?' were asked and the data searched to try to find some indications. Again, this procedure is similar to the analytic induction method of seeking to confirm a hypothesis (Mason, 1994), except that, in this study, the aim is to present the divergent views rather than to present only the dominant view.

Because of the amount of data, and in the interests of accessibility, five chapters are used to present the results of the study. Chapter Three gives the descriptive statistics for the two samples - nurses from three clinical areas of work and the general population sample. Chapters Four through Seven present the findings related to each of the four separate but related areas of investigation: The Stress Experience, Fear of Death, Coping With Death and Caring for the Dying, and Effects of Caring for the Dying. Each of those four chapters will begin with a reiteration of the hypotheses and research questions, followed by any salient points pertaining to methods of investigation and analyses of data. The findings are reported and discussed in each of those four chapters. Finally, Chapter Eight presents an overview and discusses the implications of the findings.

## CHAPTER THREE

### **Results: Sociodemographics and Descriptive Statistics**

#### **3.1 - The Nursing Sample**

Table 3.1 shows the breakdown of age, grade, working hours and area of work for each of the groups within the sample of nurses. The most noteworthy aspect of this information is the age spread. 56.4 percent of the palliative care nurses were over 40 years of age compared with 40.4 percent of the psychiatric and 33.7 percent of the general nurses. Throughout the whole sample there is generally a good spread of age. Nursing grade is primarily between D and G, (85.6 percent) within the whole sample. The breakdown within groups is similar with the exception that there were no general nurses with grade higher than G. Part-time work was much more common among palliative care nurses than in the other two groups.

Table 3.1: Breakdown of Age, Grade and Hours Worked - Nursing Sample, Whole and by Group.

|              | Total Sample<br>(n=308) | Palliative<br>(n=111) | Psychiatric<br>(n=99) | General<br>(n=98) |
|--------------|-------------------------|-----------------------|-----------------------|-------------------|
| AGE          |                         |                       |                       |                   |
| 30 and under | 20.5% (n=63)            | 14.5% (n=16)          | 15.2% (n=15)          | 32.7% (n=32)      |
| 31 to 40     | 35.5% (n=109)           | 29.1% (n=32)          | 44.4% (n=44)          | 33.7% (n=33)      |
| 41 to 50     | 31.6% (n=97)            | 38.2% (n=42)          | 31.3% (n=15)          | 24.5% (n=24)      |
| 51 to 65     | 12.4% (n=38)            | 18.2% (n=20)          | 9.1% (n=9)            | 9.2% (n=9)        |
| GRADE        |                         |                       |                       |                   |
| A - C        | 7.0% (n=21)             | 9.7% (n=10)           | 4.1% (n=4)            | 7.2% (n=7)        |
| D - G        | 85.6% (n=225)           | 70.9% (n=78)          | 88.8% (n=97)          | 92.8% (n=90)      |
| H +          | 7.4% (n= 22)            | 9.7% (n=15)           | 7.1% (n=7)            | —————             |
| HOURS WORKED |                         |                       |                       |                   |
| 1 to 25      | 19.3% (n=59)            | 30.9% (n=34)          | 6.1% (n=6)            | 19.6% (n=19)      |
| 25 +         | 80.7% (n=247)           | 69.1% (n=76)          | 93.9% (n=93)          | 80.4% (n=78)      |
| SITE         |                         |                       |                       |                   |
| Hospital     | 55.7% (n=171)           | 4.5% (n=5)            | 75.8% (n=75)          | 92.9% (n=91)      |
| Hospice      | 24.4% (n=75)            | 65.5% (n=72)          | 2.0% (n=2)            | 1.0% (n=1)        |
| Community    | 19.9% (n=61)            | 30.0% (n=33)          | 22.2% (n=22)          | 6.1% (n=6)        |

Only 41 (13.3 percent) of the 308 respondents were male, 35 of whom were psychiatric nurses, two worked in palliative care and four were general nurses. The implications of this are important when interpreting results because, where any gender effect is evident in whole-sample results, the effect may be as much related to the area of work as to gender. This makes it difficult to separate out the true effect. Because of this, it will be seen in

Chapter Five that some analyses are carried out using only female samples to eliminate the gender effect. Of the 308 nurses in the sample, 223 (74 percent) said that they have a religious faith and 191 or, 86 percent of those having a faith, believe in a life after death. 66 of the respondents, or 21 percent of the sample, had suffered a personal bereavement during the previous six months. This may be a relatively high incidence of recent bereavement, but it is impossible to know exactly how this affects the study (see also recent bereavement figures in the general population sample, below).

166 of these nurses (54 percent of the sample) had had some kind of extra training focused on palliative care and/or care of the dying patient and/or bereavement counselling. Of those 166 nurses, 99 (60%) were from palliative care, 34 (20%) from psychiatric care and 33 (20%) were from general nursing areas.

As would be expected, there was a significant (Pearson Chi-Square - 160.51, DF 6,  $p < 0.00001$ ) difference in the frequency of patient death experienced by nurses in the three groups. 60 palliative nurses (54.5 percent of the group) said they experienced patient death weekly or more often. This compares with 9 (9.2 percent) of the general nurses and no psychiatric nurses. Nearly 85 percent of the psychiatric nurses experience patient death less than monthly compared with 45.9 percent of general nurses and 16.4 percent of the palliative group. See Table 3.2.

Table 3.2: Frequency of Patient Death Experienced by Nurses in Three Clinical Areas

|                    | weekly or more | every couple of weeks | monthly    | less than monthly |
|--------------------|----------------|-----------------------|------------|-------------------|
| Palliative(n= 110) | 60 (54.5%)     | 25 (22.7%)            | 7 (6.4%)   | 18 (16.4%)        |
| General (n= 98)    | 9 (9.2%)       | 20 (20.4%)            | 24 (24.5%) | 45 (45.9%)        |
| Psychiatric(n=99)  | 0.0 (0.0%)     | 2 (2.0%)              | 13 (13.1%) | 84 (84.8%)        |

### 3.2 - The General Population Sample

The Table 3.3 shows the breakdown of ages within the general population (Gen Pop) sample (n=430) and percentage breakdown of the East Midlands region, according to the 1991 Census (percentage of the total population 18 years and over). Although there are differences, the sample used in this project represents a broadly similar breakdown of ages to that found by the 1991 Census. Of the 430 respondents in this sample, 150 were male (35 percent of the sample) and 280 (65 percent) were female. The Census reported figures



for the East Midlands region population breakdown as 48.2 percent males and 51.8 percent females.

Table 3.3: Age Ranges - General Population Compared With Census Sample

| Total sample n=430 | % (n)      | % within East Midlands region (Census 1991) |
|--------------------|------------|---|
| 18 - 30 yrs        | 17.2% (74) | 23.1%                                       |
| 31 - 40            | 24% (103)  | 17.9%                                       |
| 41 - 50            | 25% (108)  | 18.1%                                       |
| 51 - 65            | 20.5% (88) | 20.4%                                       |
| over 65            | 13.3% (57) | 20.5%                                       |

The sample used in this study, therefore, if used as a whole, may be biased by a gender factor since it contains a higher percentage of females than appears within the population of the region. Analysis of the data must take account of this. As will be seen in Chapter Five, the main comparisons with the nursing sample are carried out on only the female segments of the samples. This reduces any impact of gender bias in the sample. The sample characteristics also raise the question of why more females than males responded to the survey and whether the answer lies in attitudes to death, in attitudes to postal surveys or in the actual demographic characteristics of the target population. This is a question which will not be answered in this study.

Forty-seven people (11 percent of the sample) report being bereaved within the previous six months. This may seem to be a high rate of bereavement within the sample and, again, may reflect some relationship between bereavement and attitudes to death or attitudes to responding to the survey. It is impossible to know whether recent bereavement would tend to encourage or discourage response to such a survey.

In this sample, respondents were asked to give their occupation as well as the occupation of the head of their household. Responses to these questions were used to categorise the respondents into socio-economic groups to determine whether the sample represented a fair cross-section of society in this way. The socio-economic grouping was based upon a method given in the "1991 Census Definitions - Great Britain", page 41, 7.64. Table 3.4 shows the grouping of this sample and comparison with the percentage breakdown of a ten percent sample of the East Midlands region as given by the 1991 Census.

The socio-economic grouping allotted to each case in this sample was predominantly based on the occupation of the head of household but, where the respondent's occupation

indicated a higher status than the head of household, the respondent's occupation was used as the basis for grouping. The researcher acknowledges that some decisions about this grouping must have been of an arbitrary or interpretive nature. Further, there are some differences in spread of representation of different categories. However, for the purposes of this study, the data suggests an adequate sampling to reduce serious bias resulting from socio-economic grouping.

Table 3.4: Socio-economic Group Breakdown of General Population Sample Compared With Census Sample

| Socio-economic Group         | Sample used<br>Total n= 430 (%) | Census Report on<br>10% sample (%) |
|------------------------------|---------------------------------|------------------------------------|
| Professional                 | 67 (15.6%)                      | 5.3%                               |
| Managerial and technological | 53 (12.3%)                      | 29.6%                              |
| Skilled - non-manual         | 53 (12.3%)                      | 12.2%                              |
| Skilled Manual               | 25 ( 5.8%)                      | 27.8%                              |
| Semi-skilled                 | 96 (22.3%)                      | 15.0%                              |
| Unskilled                    | 49 (11.4%)                      | 5.5%                               |
| Armed Forces members         | 14 ( 3.3%)                      | 1.5%                               |
| Retired or unspecified       | 73 (17.0%)                      | 3.1%                               |

Note: Census (1991) percentages based on 10% sample for East Midlands region, socio-economic grouping by occupation of head of household.

This study compares results from the two samples, nurses and general population, on the 'Fear of Death' questions (see Chapter Five). Important differences in the makeup of the two samples will be addressed in that chapter.

## **CHAPTER FOUR**

### **Results and Discussion : The Stress Experience For Nurses**

#### **4.1 - Introduction**

##### **4.1.1 - Hypotheses and Research Questions**

**Hypothesis a)** There will be no significant difference across the three groups of nurses on levels of psychological well-being as measured by GHQ-12 or Burnout.

**Hypothesis b)** Appraisals of the importance of a range of stressors will vary as a function of clinical area of work.

**Question a)** Is the stress associated with patient death perceived to be different from other work-related stress?

**Question b)** What are the coping strategies reported by nurses as used and found most effective to deal with work-related stress and, in particular, to deal with patient death?

##### **4.1.2 - Procedure**

Information to test hypotheses and answer the more open-ended questions was gathered through the use of the Sources of Stress questionnaire, the GHQ-12, the MBI, and question 16 of the purpose designed questionnaire, as well as through interviews and diaries (see Chapter Two).

##### **4.1.3 - Data Analysis**

Information from the 'Sources of Stress' questionnaire was studied from two perspectives. First, frequency statistics were examined to determine the numbers and percentages of the sample reporting each item as either 'quite stressful' or 'extremely stressful' (Method 1). One weakness of this method is that if a particular source of stress, for example 'staff relationships', is rated as 'highly stressful' for 20 per cent of the sample, one could suggest that there may be a localised problem pertaining to a specific group or management. For example, when rating a potential stressor, if four subjects score 5,3,3,3, using Method 1,

only one of those four subjects would be accounted for as rating 'quite' or 'extremely' stressful. Yet when one looks at the four scores, it is obvious that the other three subjects (who score 3) rate the stressor as 'somewhat' stressful. If however, the sums of all of the case scores (using the example above :  $5+3+3+3 = 14$ ) on the items are compared, the picture of relative importance of a source of stress across the sample is perhaps more accurate, for it accounts for the situations where lower levels of stress are affecting greater numbers of nurses. To this end, data were recoded to eliminate scores of 1 for 'not stressful' and totals taken for all case scores on individual items (Method 2).

For the more qualitative investigation, a system of filing cards was used with both interview and diary material to draw out and record themes and significant ideas or statements about 'sources of stress' and 'effects of stress'. The cards from each interview and diary were studied to find information which supported, contradicted or helped to explain the quantitative results. Transcriptions of the interview tapes were used to highlight any information which related to differences between stress related to patient death and other sources of work-related stress. See Chapter Two for discussion of analysis of qualitative data.

Data from question 16 of the purpose-designed questionnaire asked nurses about coping strategies. Respondents were invited to list the ways in which they coped with work-related stress, to say which strategy they considered to be most effective and to specify whether they used the same strategies to cope with all work-related stress or had a 'special' strategy for coping with patient death.

As the data were read, strategies listed were coded under the following headings to encompass all reported strategies: Problem-solving approaches (eg taking practical steps to sort difficulties or setting clear boundaries between home and work), Avoidance/distancing/denial (reading, movies, keeping busy, thinking about other things), Tension reduction (hypnosis, shouting, physical exercise), Substance use/abuse (caffiene, nicotine, food or alcohol), Religion (faith and prayer), Reflection/personal space (time out and being alone, thinking about one's own life), Social support (talking to others, going home to family), and Professional help (counselling of some kind).

## **4.2 - Findings**

### **4.2.1 - Current Experience of Stress**

**Hypothesis 1(a)**: There will be no significant difference across the three groups of nurses on levels of psychological well-being as measured by GHQ-12 or Burnout (MBI).

In order to assess the experience of stress among nurses within this sample, the shortened version of the General Health Questionnaire (GHQ-12, Appendix II d) was used as a measure of well-being and the Maslach Burnout Inventory (MBI, Appendix II e) was used to measure the incidence of symptoms of burnout. These measures allowed comparison across the three groups of nurses.

On the GHQ-12, the maximum possible score (using Likert-type scoring) is 36. Table 4.1 shows that the mean score for the overall sample of 302 who completed the scale was 13.80 (SD 6.09). There were no significant differences between groups of nurses (using Kruskal-Wallis 1-Way Anova). When data were recoded to use the GHQ method of scoring, 32.5 percent of the sample had scores higher than three (2-3 is the recommended threshold score, above which is regarded a 'case' with psychiatric disorder, as given in the GHQ Manual). Those respondents having the high scores were evenly spread over the three groups (see Table 4.1). Thus, in terms of GHQ-12, the hypothesis was accepted.

Table 4.1: Mean Scores, Standard Deviations on GHQ-12 for overall and separate nursing groups using Likert-type scale and numbers of cases >3 using threshold rating

| Group                 | GHQ-12 - Likert-type scale<br>Mean Scores (Stand Dev) | Significance<br>of differences | GHQ-12 - threshold rating<br>No cases >3 (% of group) | Significance<br>of differences |
|-----------------------|---|--------------------------------|---|--------------------------------|
| Overall<br>(n=302)    | 13.80 (6.09)  |                                | 98 (32.5 %)   |                                |
| Palliative<br>(n=110) | 14.35 (6.17))   | NS                             | 39 (35.5)   | NS                             |
| Psychiatric<br>(n=95) | 13.49 (5.80)  | NS                             | 27 (28.0%)  | NS                             |
| General<br>(n=97)     | 13.47 (6.30)  | NS                             | 32 (33.0)   | NS                             |

The MBI scores are shown in Table 4.2 alongside the mean scores and standard deviations given for medical workers in the MBI manual (page 9). Mean scores for this overall sample of nurses and for each group are within the 'moderate' category and fall within the 'average' range as experienced by the overall normative sample (MBI manual, page 3 - page 67, this document).

Using the normative data from medical workers (physicians and nurses) (MBI manual, page 3) , 22 nurses (or 8 percent of the sample of 271 nurses who completed this scale) fall within the 'high burnout' area of scoring. Of the 22, three were palliative care nurses, 13 psychiatric and six were general nurses. 17 of these nurses were female and five males.

Table 4.2: Mean Scores and Standard Deviations (SD's) for Maslach Burnout Instrument (MBI) for Nurses, Whole Sample and by Groups from Three Clinical Areas

|  | Emotional Exhaustion<br>Mean (S D) | Depersonalisation<br>Mean (S D) | Personal Accomplishment<br>Mean (S D) |
|--|------------------------------------|---------------------------------|---------------------------------------|
| MBI manual (p 9)<br>means and SD's for medical workers<br>(n=1104) | 22.19 (9.53)                       | 7.12 (5.22)                     | 36.53 (7.34)                          |
| Nurses - Overall sample - (n=271)                                  | 19.94 (10.38)                      | 5.11 (4.71)                     | 34.29 (7.66)                          |
| Palliative (n=98)  | 17.12 (10.64)                      | 3.60 (3.35)                     | 35.01 (7.67)                          |
| Psychiatric (n=88)   | 22.82 (7.38)                       | 6.97 (5.33)                     | 34.13 (7.34)                          |
| General (n=85)   | 20.21 (10.49)                      | 4.93 (4.76)                     | 33.62 (7.94)                          |

Seven of the 22 were under 30 years of age, ten were aged between 31 and 40, four were between 41 and 50 and one nurse was over 50. The finding that the psychiatric group contained the largest number of 'high burnout' scores accounts for the fact that, using Kruskal Wallis 1-Way Anova, there are significant differences between the three groups on scores for 'emotional exhaustion' (EE, Chi-Sq 15.55, DF 2,  $p<0.001$ ) and for 'depersonalisation' (DP, Chi-Sq 20.64, DF 2,  $p<0.0001$ ), with psychiatric nurses scoring highest. Thus, the hypothesis 1(a) was rejected, in terms of burnout scores. When the whole sample was divided into those working less than 26 hours per week and those working 26 to 40 hours per week, there was a significant difference (Mann-Whitney U,  $p<0.001$ ) in mean scores on the 'emotional exhaustion' element of burnout. This helps to explain the above findings because the sample of psychiatric nurses included more full-time workers than either of the other two groups.

The mean scores for this sample, overall and by group, are generally just below those given in the MBI manual for medical workers. However, examination of the data shows that, of the 74 cases who scored in the top third of the range on emotional exhaustion, many also score within the high burnout range for either depersonalization or personal accomplishment but not on both (as required to categorise the case into 'high burnout' range). This suggests that symptoms of burnout may be more prevalent in the sample than is indicated by the 8 percent whose scores may be categorized as 'high'.

#### 4.2.2 - Sources of Stress

Hypothesis 1(b) - Appraisals of the importance of a range of stressors will vary as a function of clinical area of work.

##### 4.2.2.i - Quantitative Findings

Respondents were asked to rate a list of 24 potential sources of stress as being either 'not stressful', 'only occasionally stressful', 'somewhat stressful', 'quite stressful' or 'extremely stressful' (Appendix IIc). Table 4.3 illustrates the top 14 sources of stress measured by

Table 4.3: Self-Rated Most Important Sources of Occupational Stress (top 14 from list of 24, METHOD 1)

| Source of stress (% of total)                                 | Clinical Group n (%)  |                       |                   |
|---|-----------------------|-----------------------|-------------------|
|   | Palliative<br>(n=111) | Psychiatric<br>(n=99) | General<br>(n=98) |
| 1 Difficult/violent patients (45.7)                           | 46 (41.4)             | 46 (46.5)             | 47 (48.0)         |
| 2 Too much work/ too little time (44.4)                       | 38 (34.2)             | 51 (51.5)             | 47 (48.0)         |
| 3 Inadequate staffing in unit (42.1)                          | 32 (28.8)             | 46 (46.5)             | 49 (50.0)         |
| 4 Inability to meet patients needs* (41.2)                    | 36 (32.4)             | 44 (44.4)             | 46 (46.9)         |
| 5 Inadequate understanding/support from senior staff (39.9)   | 39 (35.1)             | 39 (35.1)             | 40 (40.8)         |
| 6 Being asked to do tasks outside my competence (35.8)        | 31 (27.9)             | 40 (40.4)             | 35 (35.7)         |
| 7 Shortage of resources in unit (31.3)                        | 13 (11.7)             | 46 (46.5)             | 36 (36.7)         |
| 8 Incompetent/unqualified staff (30.8)                        | 20 (18.0)             | 30 (30.3)             | 42 (42.9)         |
| 9 Dealing with relatives (30.3)                               | 33 (29.7)             | 28 (28.3)             | 31 (31.6)         |
| 10 Death of my patient (29.7)                                 | 23 (20.7)             | 33 (33.3)             | 34 (34.7)         |
| 11 Caring for critically ill patients (28.0)                  | 19 (17.1)             | 28 (28.3)             | 36 (36.7)         |
| 12 Lack of opportunity for personal growth/advancement (27.6) | 16 (14.4)             | 31 (31.3)             | 37 (37.8)         |
| 13 Necessity to give of myself continually (26.3)             | 31 (27.9)             | 28 (28.3)             | 21 (21.4)         |
| 14 Lack of control over decisions about patient care (25.4)   | 16 (14.4)             | 31 (31.3)             | 30 (30.6)         |

Percentages and Numbers (by group) of respondents rating items as either 'QUITE STRESSFUL' or 'EXTREMELY STRESSFUL'

\* Qualitative information reveals that this may be as a result of shortage of time OR resources OR simply because of the inadequacies of modern medicine ie inability to make patient comfortable or control pain - requires clarification.

Method 1 (the numbers and percentages of the total sample and within each nursing group who indicated particular sources of stress as either 'quite stressful' or 'extremely stressful').

At least 25 percent of the overall sample rated these 14 sources of stress as either 'quite stressful' or 'extremely stressful'. Number 1 on this list is 'very difficult/violent patients' (45.7 % of the sample) followed by 'too much work/too little time' (44.4%), 'inadequate staffing in unit' (42.1 %) and 'inability to meet patients' needs' (41.2%). From the table one can also see that there are some group differences. Most noteworthy of these are the ratings on 'shortage of resources in the unit', 'incompetent/unqualified staff' and 'lack of opportunity for growth/advancement'. Chi-Square statistics from the Crosstabs procedure on the SPSS program show significantly fewer of the palliative group rating these as important sources of stress ( $p<0.001$ ). 'Inadequate staffing in unit', 'caring for critically ill patients' and 'lack of control over decisions about patient care' are also rated as serious sources of stress by fewer palliative care nurses ( $p<0.01$  on all items). Although palliative care nurses experience greater frequency of patient death, fewer of that group rate 'death of my patient' as 'quite stressful' or 'extremely stressful' ( $p<0.05$ ). Fewer palliative care nurses complain of 'too much work/too little time' as a stressor ( $p<0.05$ ). Thus the hypothesis was accepted and the appraised importance of stressors does vary as a function of clinical area of work.

Using the second method of analysis (Method 2 - using total of all case scores on each item, a method which accounts for more situations where lower levels of stress may be affecting greater numbers of nurses), the same 14 sources of stress rate highest and there

Table 4.4: Self-Rated Most Important Sources of Occupational Stress (top 14 from list of 24, METHOD 2) -

| Source of Stress - number indicates order of importance (OI) for overall sample | Overall Score | Palliative (OI) | Psychiatric (OI) | General (OI) |
|---|---------------|-----------------|------------------|--------------|
| 1 Too much work/too little time   | 674           | 205 (2)         | 237 (1)          | 232 (2)      |
| 2 Inadequate staffing in unit   | 654           | 190 (5)         | 227 (2)          | 237 (1)      |
| 3 Difficult/violent patients  | 650           | 214 (1)         | 210 (5)          | 226 (4)      |
| 4 Inability to meet patient need  | 649           | 197 (4)         | 225 (4)          | 227 (3)      |
| 5 Inadequate understanding/ support from senior staff                           | 612           | 187 (6)         | 226 (3)          | 199 (11)     |
| 6 Dealing with relatives  | 573           | 203 (3)         | 185 (9)          | 185 (12)     |
| 7 Death of my patient   | 566           | 183 (7)         | 179 (11)         | 204 (8)      |
| 8 Being asked to do tasks outside my competence                                 | 560           | 166 (9)         | 193 (6)          | 201 (9)      |
| 9 Shortage of resources in unit   | 540           | 115 (19)        | 225 (4)          | 200 (10)     |
| 10 Caring for critically ill patients   | 530           | 156 (10)        | 167 (14)         | 207 (6)      |
| 11 Lack of opportunity for personal growth or advancement                       | 524           | 132 (15)        | 187 (8)          | 205 (7)      |
| 12 Incompetent/unqualified staff  | 518           | 129 (16)        | 181 (10)         | 208 (5)      |
| 13 Necessity to give of myself continuously                                     | 511           | 181 (8)         | 175 (12)         | 155 (17)     |
| 14 Lack of control over decisions about patient care                            | 502           | 136 (13)        | 190 (7)          | 176 (13)     |

Total Case Scores and Order of Importance (OI) and for individual items (POTENTIAL SOURCES OF STRESS) by group and in overall sample



are only slight changes to their order of importance. Table 4.4 gives the order of importance (OI) and total case scores by group and for the overall sample. This table also highlights the differences in ratings across the three groups. For example, 'inadequate understanding/support from senior staff' appears to generate more widespread stress in the psychiatric nursing sample while 'dealing with relatives' appears to be more stressful for the palliative care group and 'incompetent/ unqualified staff' is widely rated as a stressor by the general nurses.

For almost 30 percent of the sample 'death of my patient' was rated as 'quite stressful' or 'extremely stressful' and, overall, ranked tenth on the list of important stressors. Using Method 2 (totals of all case scores), this item rose to seventh place on the list of stressors for the overall sample and patient death was ranked as a less important source of stress for psychiatric nurses than for general or palliative care nurses. In part, this reflects the fact that psychiatric nurses in this sample experience patient death less frequently than the other two groups. However, using Method 1 (ratings of degree of stress), the same proportion of the group find patient death 'quite' or 'extremely stressful'. When results of both methods are considered, the data suggests that patient death, when it occurs, is as stressful for those psychiatric nurses as for general nurses.

To summarize, the hypothesis 1(b) is accepted and appraisals of the importance of a range of stressors do vary as a function of the clinical area of work. Although there are significant differences among the three groups on ratings for particular sources of stress, the five most important sources of stress in the overall sample are a) 'too much work/too little time', b) 'Inadequate staffing in the unit', c) 'Difficult/violent patients', d) 'Inability to meet patient's needs', and e) 'Inadequate understanding/support from senior staff'. Although patient death is not in the 'top five' sources in these ratings, it is still considered to be a substantial source of stress (rated seventh). Despite the frequency with which patient death is encountered, it is rated as 'quite' or 'extremely' stressful for significantly fewer palliative care nurses.

On the questionnaire, 88 percent of the sample chose to write answers to one or more of the open questions (Appendix Iij) which asked about other losses suffered at work, least/most rewarding aspects of work and main frustrations at work. Nurses who

responded to these questions listed 'loss of staff and colleagues', 'loss of management' and 'loss of nursing ethos' as other losses suffered at work. Qualitative data from these open questions and the data from interviews and diaries were compared with the quantitative data on sources of stress.

#### 4.2.2.ii - Qualitative Findings

The qualitative data provided considerable support for quantitative findings in respect of sources of stress. For example, in response to the open questions in the questionnaire, described above, 'staff shortages' or 'too much work/too little time' were given as 'the most frustrating aspect' by 23 percent of those who answered. The second most frustrating aspect was 'communication problems', written about by 17 percent of those responding. These communication problems were between staff members, staff and management and between departments. The 'most rewarding aspects' of work were said to be 'successful outcomes for the patient', by 21 percent of those responding to this question, and 'being able to give good holistic care and achieve patient comfort', by 17 percent. Staff shortages, workload which resulted in insufficient time to give good holistic care and lack of understanding and support from management were also commonly reported in interviews and diaries as sources of stress.

Qualitative data also informed that, as well as perceptions of stress caused by some situations, specific emotions were recognised by nurses as resulting from these stressful situations. When staffing difficulties prevent the nurse from giving the quality of care which they have been trained to give and recognise as desirable, some nurses reported feeling uncomfortable, angry and even guilty about the situation. As an example:

*" One of the ladies, I've had her let down since admission because basically she didn't need a lot of physical care, but she needed a lot of psychological care and she was vomiting and so forth.... and I felt that I hadn't had the time to sit down and talk through with her anxieties and so forth, because I was too busy, because no staff had been allocated for the other two teams so therefore I was delivering care in those two teams 'cause they (needs of the patients) were physically heavier, .....and then when I actually got around to seeing her in the afternoon, she was with relatives and she was on the phone and I just felt I'd let her down.....I felt quite angry inside myself for not making*

*that time for her, I felt quite demoralized I must admit...I felt very guilty, yeah.*” (INT 4 - PALL)

Most of the other potential sources of stress listed in the questionnaire (see Appendix IIc) were mentioned by one or more nurses at some point in interview or diary data. In addition, several other sources of stress emerged from qualitative data, most notably ‘change’. It became obvious that, for many of the units involved, this ‘change’ related to the recent move to Trust status and/or the changes related to recent legislation regarding Community Care and the Patient's Charter. Change, especially within the psychiatric nursing group, was said to be stressful, mainly because of a lack of information, lack of consultation and, in some cases, because of a lack of sufficient staff to implement the changes smoothly. For some nurses in the general nursing group, changes of shift patterns which had been imposed on nurses had caused a great deal of stress because these changes upset the balance of work/home obligations which had been in place for some time (for example child-care arrangements).

The interviews and diaries gave further support to the finding that sources of stress differ in importance across groups of nurses. ‘Night travelling’, ‘watching the suffering of the chronically ill’ and ‘being the focus for patients’ everyday hassles’ were reported by community nurses as stressful parts of their work. Some psychiatric nurses who work with the elderly dementia sufferers said that their work was stressful because it is monotonous and gives little opportunity ‘to get results’ which produce job satisfaction. Patients in these units do not recover from their illnesses and are frequently unable to communicate with others. As one psychiatric nurse put it, *“You must look for job satisfaction in different ways than in other areas of nursing”* (INT 14). The nurse explained that toileting of a patient, rather than simply changing soiled linen, became a way of maintaining dignity and a better quality of life for a patient. Although the patient may not even be aware of his/her surroundings, for the nurse, this became a way of achieving job-satisfaction, through the knowledge that he/she was giving the best possible care to the patient.

‘Quality of care given in the unit’, as a potential source of stress, did not fall within the top 14 sources in the quantitative ratings (Table 4.3 and Table 4.4). However, qualitative findings revealed that this was a major concern for some nurses. Ethical questions about

quality of treatment and the quality of life experienced by patients were raised by nurses from all three areas. Largely, nurses from palliative and general clinical areas referred to situations surrounding terminally ill or dying patients and these are discussed in Chapter Six. However, psychiatric nurses had some specific concerns regarding care of their patients. Psychiatric nurses working in acute units said that the constant need for high intensity observation and watchfulness required to maintain control on their units was a major stressor. In one acute unit, concerns were expressed about patients simply being controlled rather than being given time, counselling and attention (INT 8) required to improve their mental health. This was largely attributed to lack of staff and was seen as a failure to provide adequate care. Another important source of stress was the need to adhere to rules and regulations while still dealing with events on the ward, when there were insufficient numbers of staff to do so properly. An example given (INT 8) was the regulation that, for protection of patient and staff, restraining of a patient required a three-person team. If there was more than one incident occurring at the same time, a frequent possibility on an acute ward, it became impossible to adhere to regulations and still do the job.

In an elderly care psychiatric unit, some nurses were concerned that physical needs of the elderly demented were inadequately and/or inappropriately dealt with (INT 14). The nurses' perception seemed to be that, sometimes, other members of the medical professions held a rather diffident attitude to physical care of the elderly demented. This qualitative data underlines the importance of 'inability to meet patients' needs' which ranked highly as a source of stress in the quantitative assessment (Table 4.3 and Table 4.4).

#### 4.2.3 - Patient Death as a Stressor

Research Question 1a) Is the stress associated with patient death perceived to be different from other work-related stress?

Patient death was rated as an important source of stress, as high as seventh on a list of 24 (Table 4.4), but, in interviews, several nurses cautioned against the assumptions that this event is always very stressful and that working with the dying is "all doom and gloom". In findings similar to those of Fisher (1991), nurses in this study made it clear that there could

be much job satisfaction attached to the work involved and that the job satisfaction could act as a counter-balance to the stressful aspects. Further, some nurses explained how small incidents can create more stress than a patient death. For example:

*"...the one night it was a shortage of milk, the next night it was a shortage of tea bags and the night after that there was a shortage of cups to put the milk and the tea in, so it's an accumulation of three isolated incidents that together are quite frustrating, which actually are the same department's management problem. They are not a real issue at two o'clock in the afternoon but at two o'clock in the morning they are....At two o'clock in the afternoon you can pick up a telephone providing it's Monday to Friday...and phone the catering department and they will send somebody along with the tea bags. At two o'clock in the morning you have got to send somebody from your ward to another to see if they've got any tea bags to spare 'cause they could be in a similar situation to you and if they haven't then you move to the next ward and you're talking about the middle of the night, minimum staffing levels - where possibly a third of your staff - one person - is absent from the ward.. ....It's a major problem, yet in itself it's quite trivial." (INT 1-GEN)*

Similarly, for the community nurse, a traffic jam can make them late for an appointment, resulting in a distressed or angry patient and a nurse who is tense and anxious about getting to the next appointment (D11-PALL). The negative effect of that incident may be continuous throughout the remainder of the day. On the other hand, while a patient death is always a source of sadness, in some circumstances the event may not actually cause stress.

*".....some deaths which are expected, you are prepared and the relatives are prepared, you may not feel any stress at all but you may get an overwhelming feeling of just job satisfaction, I've done my job well here." (INT 1-GEN)*

The above quotation highlights the importance to the nurse of being prepared for a death and of having the relatives prepared for the death. It also emphasises that job satisfaction can be found in caring for dying patients. These points will be discussed in more detail in Chapter Six.

Interview data provided valuable information which added detail to an understanding of how nurses perceive the stress associated with patient death. For example, the data informed about why patient death ranks higher than other sources of stress for many nurses. Most of those nurses who were interviewed endorsed the view that stress which is related to working with the dying and to patient death differs from that related to other aspects of work. One prevalent explanation for this difference was that the stress related to patient death touches the nurse at an *"emotional and spiritual level"* (INT 11-GEN/PALL). There is *"an overlying sadness"* (INT 3-PALL) to every experience of caring for the dying patient, often followed, after patient death, by a sense of loss and bereavement.

Other sources of stress such as workload or administration problems may produce feelings of frustration and anger but the problems can be tackled, dealt with and forgotten. *"You can turn off other problems but not patient death - it stays a long time"* (INT 11-GEN/PALL). Patient death may leave the nurse with feelings of *"not having lived up to expectations"* resulting from *"questions you can't answer, pain you can't control, distress you can't help"* (INT 23-GEN). When dealing with patient death, *"there is no opportunity to correct mistakes...if it goes wrong, there is nothing that will make it right"* (INT 25-PALL).

Feelings related to patient death can be harder to dispel and some nurses said that *"there are some deaths which you never forget"* (INT 11-GEN/PALL). The nature of the nursing ethos of caring for people means that *"you are geared up to think about patient death differently - you go home and think about it"* (INT 9-GEN). However, one nurse, working in elderly care, felt that stress associated with patient death was sometimes easier to cope with because one could see the reason for the death (of elderly patients) (INT 6-GEN) and patient death was an event which *"is over"* whereas administration problems may accumulate, a view also expressed in an interview with a general ward nurse (INT 1).

#### 4.2.4 - Coping Strategies

Research Question 1b) What are the coping strategies reported by nurses as used and found most effective to deal with work-related stress and, in particular, to deal with patient death?

Nurses were asked to list their own ways of coping with work-related stress (Appendix Iib, question 16) and the findings were coded and quantified as stated above. Half of those nurses who completed the questionnaire indicated the use of more than 2 coping strategies to deal with work-related stress. The four most common categories of coping strategies were 'seeking social support' (n=254 of whom 186 (73 percent) gave this as most effective strategy), 'avoidance/distancing/denial' (n=204 of whom 41 (20 percent) listed as most effective), 'tension reduction' (n=153 of whom 39 (25 percent) listed as most effective) and 'substance use/abuse' (n=109 of whom only seven (six percent) listed as most effective).

Although only eight respondents gave problem-solving types of strategies (aimed at reducing the problem), it is acknowledged that some other strategies could be considered as part of that category. For example, talking things over with a colleague may reduce staff tensions and may be seen as a problem-solving approach in that instance. However, there was little evidence, in this section of the data, of nurses using a structured problem-solving approach such as 'planning time better', 'sharing workload more effectively' or 'changing routines to be more efficient'. It is possible that nurses do take these or similar actions but do not consider them to be coping strategies. 17 nurses gave 'religion' or 'prayer' or 'faith' as one of their strategies and eight respondents stated that they sought professional help or counselling.

Coping strategies were studied in relationship to those scoring high/low on GHQ-12 (> 3 or ≤ 3) and MBI (within the 'high' range on emotional exhaustion and depersonalization). Percentages of the groups using each coping strategy were very similar. Table 4.5 shows numbers and percentages of the high/low scoring GHQ-12 groups who reported using certain coping strategies together with figures for the overall sample to allow comparison.

There appears to be little sign in these data of particular coping strategies being associated with high/low well-being. However, this may reflect the methodology used to ascertain reported coping strategies. Since each respondent was asked to report their coping strategies, rather than choose from a list, some respondents listed only one strategy and others listed as many as four. This makes it particularly difficult to separate out the effect on well-being of any individual coping strategy.

Table 4.5: Coping Strategies used - Numbers and (percentages) by group (High/Low GHQ-12) and overall sample

| Coping Strategy   | GHQ-12 scores = < 3<br>(High wellbeing)<br>n=204 | GHQ-12 scores > 3<br>(Low wellbeing)<br>n=98 | Overall sample<br>n=308* |
|-------------------|--|--|--------------------------|
| Problem Solving   | 6 (3%)   | 2 (2%)                                       | 8 (3%)                   |
| Avoidance         | 132 (65%)  | 68 (69%)                                     | 204 (66%)                |
| Tension Reduction | 104 (51%)  | 49 (50%)                                     | 153 (50.0%)              |
| Substance Use     | 66 (32%)   | 41 (42%)                                     | 109 (35%)                |
| Social Support    | 163 (80%)  | 85 (87%)                                     | 254 (83%)                |
| Religion          | 12 (6%)  | 5 (5%)                                       | 17 (6%)                  |
| Reflection        | 13 (6%)  | 12 (12%)                                     | 25 (8%)                  |
| Professional Help | 3 (1%)   | 2 (2%)                                       | 8 (3%)                   |

\*Note that discrepancy in numbers results from some respondents failing to complete GHQ-12 and most respondents listed more than one coping strategy.

#### 4.2.4.i - Sources of Social Support

It would appear that colleagues are the most important source of support. One question asked "When dealing with stress which is related to work, to whom do you turn for support? (Appendix IIj). The choice of reply was a) spouse or partner, b) friends, c) colleagues and d) professional help. Coding of responses for analysis allowed for multiples of these. 26.7% of the sample gave only colleagues. A further 43.5% gave multiple answers which included colleagues. Thus, more than 70% of the sample depend on colleagues, at least in part, for support. In this respect, Chi Square tests showed no significant difference across the three groups.

Qualitative data informed that some nurses may not be able to depend on family for this kind of social support because of the nature of their work experience. For example, one hospice nurse said *"I don't talk to the family much...they don't want to listen"* (INT 24-PALL).



The methods of getting that support from colleagues were investigated during the second phase of the work, during interviews and from diaries. It appears that this support was largely sought and given on an informal basis. For example, interviewees explained that they would arrange a night out to socialise together or they would go swimming together after work or just chat on the way home or over the telephone. The support may simply be given on an as-needed basis when a member is distressed.

However, some units take a more structured approach to dealing with work-related stress, particularly the stress associated with traumatic events such as patient death. One approach which was reported was to have staff meetings, the purpose of which is to address the issues which are causing problems. Some nurses said that these meetings were less than effective because staff were unable to say what they really felt for fear of being seen as 'not coping'. Sometimes, nurses said, the timing of the meetings meant that it was too soon after a traumatic event for them to be able to talk - they needed time to work through things in their own minds first. There were also comments that these meetings became focused on practical issues and did not always allow for venting of more emotional feelings. However, one nurse made the point that it is sometimes easier to air one's views on patient death than on other issues of the workplace, and support can be more forthcoming from colleagues when related to patient death than with other issues. For example, where staff conflicts are concerned, one can be isolated and feel unsupported (INT 16-PSY).

An example of successful staff meetings was given by a nurse (INT 5-PSY) who reported a more-or-less unspoken rule that if there was an incident in their unit which may have caused any kind of stress, trauma, or anxiety, the staff would meet for ten minutes at the end of the shift, perhaps for a quick cup of tea, and discuss the incident. The meetings are usually short and quite informal but they occur almost every day. The length of the meeting is determined by need and sometimes the staff will talk for some time. If it is considered necessary, they agree to meet early for the next shift to talk again before they begin work. This approach was said to do two things. It helps members to cope with the stress and to resolve issues which may arise in future situations. The meeting also allows the staff to leave work behind when they go home at the end of the shift, establishing a boundary between work and home.

#### 4.2.4.ii - Boundaries

Setting clear boundaries between home and work appears to be a major key to coping with the stress for many nurses. This may be aided by staff discussions before leaving work, as mentioned above. Further, the journey home at the end of a shift is often used to establish the boundary by winding down, letting off steam or recognising the change of role from nurse to mother, as explained by the following extracts.

*"When I had this job I had a choice between one which was about 5 minutes down the road and this is between 20 - 25 minutes but I took this because I need that time to unwind. I play music and that 20 minutes is very transitional for me. ....I think I probably do quite a lot of processing in that time....occasionally I do take things home but....I'm quite strict on boundaries.....When I'm at work I'm very much at work and when I'm at home I'm there." (INT 15-PSY)*

*"...I'm quite lucky because I've got quite a drive home ....so I usually have a good temper tantrum down there...I used to play my cassette...I have shouted, cried...and then usually I have to go and pick up my daughter so I have to click into that mode." (INT 4-PALL)*

Another very experienced hospice nurse spoke of the boundaries or limitations which one must put in place if one is to do this work on a long-term basis.

*"You can limit your stress by not making yourself the only person that the family will relate to....you feel that the family can't do without you...that does cause stress because a lot of the time you are trying to achieve things that are not possible. You have to set boundaries around what you are prepared to give. If I want to carry on this work I have to protect myself....by having the boundaries which I don't overstep...by using colleagues....take a break ...hand over to other staff." (INT 25-PALL)*

#### 4.2.4.iii - Avoidance Strategies

It also became very clear that nurses do use detachment and avoidance strategies to cope, particularly in the very stressful situations and in times when they feel overloaded. For example, a nurse who worked in a casualty unit when she was young explained:

*"I found what you have to do is remain very detached from the person - not the needs or the incident .. but you very rarely thought of the person as a whole..... At that time I found it was helpful not to think too deeply.....It was like a selfish kind of nursing...you could enjoy your work but stay detached.....Youth and inexperience probably helped me...now if I find myself confronted by similar (situations), I become very emotional.....I wouldn't be able to apply that detachment now." (INT 19-GEN/PALL)*

One nursing manager explained that if a staff member shows signs of stress, they advise that that member *"should reflect on their practice", should "not identify with the problem", "should not stay remote but stay in control", using "empathy, not sympathy"* (INT 13-PSY). This is a strategy which appears to be difficult for many nurses to employ successfully and which, for some nurses, seems to conflict with their ideals or beliefs about the work they do.

*"Patient death does take a toll. You are a good nurse when you feel for people and I think when you stop feeling for people you should stop doing the job...so obviously it takes a toll" (INT 18-GEN)*

*"Don't get involved...don't get involved with them...and how the hell can you bloody nurse if you're not getting involved with people? I mean it's a hideous thing to say isn't it...I mean you can't not get involved. The thing is that you can get uninvolved afterwards but you have to get involved!" (INT 15-PSY)*

### **4.3 - Discussion**

#### **4.3.1 - Experience of Stress**

It has already been said that the investigation of stress in this study was meant to serve as a background against which to investigate patient death as a stressor, fear of death and nurses' perceptions and experiences of working with dying patients. It was believed that if the sample demonstrated levels of stress which were substantially different from those found in other studies of nurses, any death attitude data could be seriously affected by the levels of stress reported within the sample. Although a relationship between levels of stress and fear of death, coping with death and death self-efficacy scores would be a logical result (see Chapter Six for actual results from this study) when considered within the Lazarus and Folkman (1984) framework, if the sample reported levels of stress which were similar to those in other studies, then the reliability of the data on the other variables would be strengthened. This is especially important in view of the novelty of the death attitude portion of the work.

A standardised, commonly-used measure of psychological well-being, the General Health Questionnaire - 12 (GHQ-12, Goldberg, 1972; Goldberg and Williams, 1988), was used alongside the Maslach Burnout Instrument (MBI, Maslach and Jackson, 1981) to measure the extent to which nurses reported stress.

On the basis of results from the GHQ-12, levels of stress experienced within this sample of nurses appeared to be moderate. The GHQ-12 mean score of 13.80 for the sample (n=302) is within the range of mean scores reported by Spelten et al. (1993) in their study of 1532 nurses and midwives in England and Wales (mean scores from 10.45 to 14.55 over four sub-groups). Using the 'caseness' scoring method, 32.5 percent of the sample had scores higher than three (GHQ manual recommends 2-3 as the threshold) and 23.4 percent had scores higher than five. This finding is broadly similar to that of Tyler and Cushway (1992) who reported that 29 percent of their sample had scores higher than five. MBI scores within this sample also indicated a moderate level of burnout. The low number of palliative care nurses rated as suffering high burnout may be related to the high incidence of part-time work within this sample. Although psychiatric nurses scored

statistically higher than the other two groups, their group scores still fell within 'moderate' or 'average' ranges as given in the MBI manual.

The findings related to burnout raise a question about the method of deciding levels of burnout. The requirement for specific ranges of scores on all three elements to determine the level of burnout may be inadequate to show the true incidence of symptoms of the phenomenon. While only ten respondents in this study would be categorized as having 'high' levels of burnout, there is much greater incidence of 'high' levels of emotional exhaustion. Further, these high scores are combined with either 'high' depersonalization or 'low' personal accomplishment. It would seem to be worth considering whether, when using the MBI to assess the levels of burnout in a population, the three elements should be studied separately as well as in the manner recommended by the authors of the instrument.

It is important to reiterate the difficulties inherent in the use of self-report methods in the study of stress. It is acknowledged that nurses may decline to participate in a study which may portray them as vulnerable or 'not coping'. Those who are suffering from high levels of stress or burnout may also decline to take part. Of those who do participate, it is possible that the responses are less than accurate, either because the nurse is unwilling to expose his/her symptoms of stress or because s/he wishes to make a particular point by exaggerating the symptoms. However, the findings in this study are similar to those of many previous studies including the research by Spelten et. al. (1993) and Sullivan (1993). As a contextual basis for the death attitude portion of this study, there is no reason to believe that this sample exhibited unusual levels of stress or burnout which might affect their reported death attitudes.

#### 4.3.2 - Sources of Stress

Although there is no significant difference in the amount of negative outcome as measured by the GHQ (Table 4.1), there are some group differences in importance of rated sources of stress (Table 4.3 and Table 4.4). This concurs with the findings of Tyler et al. (1991) and Tyler and Cushway (1992). However, the psychiatric group does show statistically higher levels of emotional exhaustion and depersonalisation as measured by the MBI. One possible factor in this result may be the high percentage of the psychiatric group who work full time as compared with the other two groups in this sample within which part-time

work is more common. Mean scores for the psychiatric group are broadly similar to those reported by Sullivan (1993) for a sample of 78 psychiatric nurses from acute in-patient facilities (emotional exhaustion = 20, SD=7.05; depersonalisation = 7.4, SD=5.5). This is an important finding, providing confirmatory support for previous findings and underlining the inaccuracy of any assumption that dealing with patient death is necessarily the most emotionally exhausting part of nursing work since psychiatric nurses experience significantly fewer patient deaths than the other two groups.

While patient death is ranked as high as seventh on a list of 24 potential sources of stress (Table 4.4), it is clear that workload, staffing levels, difficult or violent patients and the inability to meet patients' needs create more stress for more nurses. This is in line with other research such as that of Cooper and Mitchell (1990) who found workload issues were major sources of stress and Tyler et al. (1991) who reported that workload was the best independent predictor of health and well-being within their sample from public and private sectors.

The interpretation of 'inability to meet patients needs' (Appendix IIc), perceived to be another of the most important stressors, is undoubtedly linked to the staffing and workload problems but may have different connotations for different nurses. The value of combining the quantitative and qualitative methodologies is underlined here because the interviews and diaries allowed nurses to speak/write in more detail about sources of stress. During interviews, and from diary writings, it became apparent that general nurses were concerned about the lack of time to provide holistic care. Several of the general nurses who were interviewed reported that while the ethos had changed over the last decade towards giving better psychological and emotional care alongside the physical care, there is too often insufficient time to do this. A lack of resources or poor management sometimes made it difficult to give the desired standards of physical care, but more often it was the psychological and emotional care which was neglected. Nurses reported that they found this stressful because of the dissonance between their training and commitment to certain standards of care and their ability to achieve those standards, but also because they were in 'the firing line' for patients' anger or complaints, especially since the introduction of the Patient's Charter which may have raised the expectations of the public.

For psychiatric nurses, particularly those working in acute units, 'inability to meet patient's needs' was sometimes related to being unable to spend sufficient time with individual patients to deliver what they see as good care. Their perception was that recent changes within this area of nursing and, more specifically, within some units involved in this study, have also meant that some patients are released into the community too soon and are frequently re-admitted. These psychiatric nurses interpreted this as a failure to meet the patients' needs in the first instance. For palliative care nurses, this issue appeared to be more often linked to the inability to control pain and provide the 'good death'. See Chapter Six for more discussion of the 'good death'.

Melia (1987), in her study of student nurses, found ample evidence of the dissonance between training and practice on the wards. Largely, the dissonance resulted from the need to 'get the work done' even though the highest standards of care were not always met. Demonstrating another convergence of the quantitative and qualitative data, experienced nurses interviewed in this study, particularly from the general and psychiatric groups, report a similar problem and contend that the problem is getting worse because of an increasing shortage of staff (rated as a major source of stress in the quantitative data - see Table 3 and Table 4). Within Melia's student sample, there appeared to be some measure of acceptance of the situation, a stance which is understandable among students in the process of learning how the ward functions. Within this sample of more experienced and mature nurses, there is an acceptance that the situation exists, but there appears to be considerable discomfiture.

The continuing expression by nurses of the importance of workload as a stressor (Table 4.3 and Table 4.4), emphasises the apparent failure to address this issue in health-care institutions. The qualitative data suggested that changes within the workplace were a source of considerable stress for all three nursing groups in this sample. These findings provide clear support for the contention by Tyler and Cushway (1992) that organisational changes compound the problems associated with workload. Llewelyn and Payne (1995) have commented that "factors precipitating the experience of stress may actually be an important component of the stability of the system within which the individual exists" (pg 112). If this is the case, does this mean that hospitals can only function when nurses are overloaded with work to the extent that their well-being is at risk? This is a question

which must surely be addressed by policy makers and those charged with the economic responsibilities for health-care.

Group differences on ratings of sources of stress support the findings of Tyler and Ellison (1994) and others that sources of stress differ across nursing groups. Some of the differences found in this study reflect the different ethos and culture within which the palliative nurses most often work. The palliative care group's lower ratings for 'incompetent/unqualified staff' may reflect the fact that nurses must take highly specialised training to work in palliative care, thereby enabling palliative care nurses to be surrounded by very high levels of competence and qualification in their colleagues. Nurses working in specialist units may share a similar perception of high levels of competence and qualification but were not represented in this study. In quantitative data, the general nursing group reported more stress associated with shortage of staff and with incompetent/unqualified staff. The qualitative data from both psychiatric and general nurses suggested that, in some cases, student nurses were perceived as incompetent and unable to complete even basic tasks of practical nursing. This may provide a partial explanation for this result. However, it is a finding which deserves further inquiry.

Palliative care nurses also rate 'lack of opportunity for growth/advancement' and 'lack of control over decisions' as lesser sources of stress. This may reflect the greater responsibility for nursing care decisions which is often given to palliative nurses. Even when final decisions rest with the doctors, nurses in terminal/palliative care may be allowed greater autonomy than nurses in other areas of work (Field, 1989). Some palliative care nurses working in the community (for example, Macmillan nurses) often have a considerable amount of autonomy in decisions about patient care. Control over decision making can, however, be a 'double-edged sword'. While a high level of control can have some benefits for the nurse, it can also make the work more stressful, especially when the nurse feels unsupported by the other members of the medical team (INT 3-PALL).

More psychiatric and general nurses report high levels of stress associated with lack of control over decisions (Table 3 and Table 4). This too, is reflected in the qualitative data, where some of the psychiatric nurses say that they are "at the mercy of the system". Nurses from an acute unit explained how they were consulted by doctors and expected to give professional advice about the condition of patients, yet had insufficient control over



when patients were released because of the pressure from management to move patients to the community. Many of the psychiatric nurses in this sample had been exposed to the repercussions of major institutional changes during the months preceeding the collection of data. For some psychiatric nurses, this has even precipitated a change of job, from working on the ward in hospital to working in the community, visiting patients in their homes. As reported in 4.2.2.ii, psychiatric nurses who were interviewed reported their dissatisfaction with communication between levels of staff, with imposed change without consultation and with new approaches to patient care, particularly where it concerned the early release of the patient into community care systems. Recent changes to management structures were also linked to 'lack of control over decision making' and it is acknowledged that this may indicate a localised problem rather than a universal one.

For general nurses, stress associated with the lack of control over decisions about patient care appears to reflect the nature of general ward nursing wherein the doctor still takes the majority of decisions and the nurse still largely plays a secondary role. The fact that this appears to be an important source of stress for these general nurses (see Tables 3 and 4) may be interpreted as providing some support for the contention, by Llewelyn and Payne (1995), that many nurses are eager to renounce this 'handmaiden' role and to take more responsibility for patient care.

It is worth noting that pay issues did not feature largely in any of the data. Although the research was carried out when nursing unions were engaged in pay negotiations and the media was writing about nurses' concerns, these concerns were not expressed by this sample. Three nurses said 'pay' was the least rewarding aspect of their work. There were nurses who said they would appreciate greater recognition and some said that "a thank you would be nice once in a while", but very few nurses mentioned issues of pay. It is clear that while pay may be important, there are other issues which take precedence.

As was anticipated, however, change has been noted several times as a source of stress for nurses in this study. Generally, for psychiatric and general nurses, the change has been related to changes of hospitals to Trust status and the management changes which have ensued as well as changes toward greater care within the community. For hospice nurses, the trend towards community care has meant a faster turnover of patients in hospices because patients arrive at hospice much closer to the end of their lives than has previously

been the case (see Chapter Six also). These findings, coupled with other concerns raised by nurses about the quality of care now given in nursing, suggest that nurses believe the ethos of nursing has changed with the recent structural and political changes. This change in ethos appears to have left nurses feeling dissatisfied with the care they are able to give in some instances. This must have strong implications for job satisfaction and morale among nurses.

For palliative care nurses in this sample, dealing with relatives was rated as a more widespread source of stress (Tables 3 and 4). This may be explained by the fact that the palliative nurses are constantly dealing with relatives who are at their most vulnerable and emotional when facing the impending loss of a loved one. A similar finding was reported by Tyler and Cushway (1992). Their sample of nurses in a Renal Unit reported high levels of stress associated with caring for the dying patient and their relatives. In this study, although they rated difficult/violent patients as major stressors, fewer palliative care nurses rated patient death and caring for critically ill patients as 'quite' or 'extremely' stressful. One difference between this sample and that of Tyler and Cushway (1992) is that the renal unit nurses would be hopeful of saving, or at least extending, the lives of many of their patients, a factor which may provide greater stress when the patient actually dies. As one nurse interviewee in this study pointed out, palliative care nurses expect their patients to be critically ill and they have come to terms with their impending death. Using the Lazarus and Folkman (1984) framework, an appraisal of stress in a patient-death situation may be moderated by these expectations as well as by the training and experience of the palliative nurses.

#### 4.3.3 - Patient Death as a Stressor

Patient death was rated as high as seventh on a list of 24 stressors. This confirms the results of many previous studies which show that nurses perceive patient death as an important source of stress (Vachon, 1987; Cooper and Mitchell, 1990; Snape and Cavanagh, 1993; Molassiotis and Van-den-Akker, 1995). Data reflect the lower frequency of patient death experienced within this sample of psychiatric nurses, but suggest that patient death, when experienced, is as stressful for those psychiatric nurses as for general nurses.

However, the qualitative data (see 4.2.3) informs that experiencing a patient death can sometimes happen without stress and can provide a source of job satisfaction. This point is important because it underlines the individuality of the stress process as explained by Lazarus and Folkman (1984). The description of a death-related situation which can result in an appraisal of no stress highlights the need for nurses to feel that they have done their job well and that they have been able to give the best possible care to their patient and the relatives. This scenario has a focus on the nurses' view after the event. Feeling confident and competent to deal with patient death and related issues before the event is also important for nurses and will, according to the Lazarus and Folkman view of stress, increase the likelihood of an appraisal of little/no stress (see Chapter 5).

In response to the research question, the overwhelming view of the nurses who were interviewed was that the stress associated with patient death is different from other work-related stress. When nurses say that this stress is different, that it touches them in a different way, it does not necessarily mean that the stress process of appraisal as described by Lazarus and Folkman (1984) differs in the event of patient death. The nurse is as likely in that situation as in any other to make a cognitive assessment of the transaction between her/himself and her/his environment to determine whether and in what way the situation might be stressful. The literature does not provide previous research on this specific question, but there is no evidence in this study to suggest that this process of appraisal changes when an individual is dealing with the event of patient death.

However, the data in this study do suggest some possible explanations for the nurses' perceptions. Accounts suggest that perceived differences in the kind of stress experienced may relate to the perceived threats created by the event of patient death, and/or perceived coping strategies available to deal with the event and/or the nature of the effects of such an event. These will be discussed in turn.

### Perceived Threats

Some accounts from nurses reveal a questioning of the use of some treatments for the terminally ill and a perception that the medical profession does not always act in the best interests of the patient. These accounts suggest that the experience of patient death may threaten a nurse's beliefs about the abilities of the nursing and medical profession as well

as threatening his/her commitments to certain aims of nursing care. One view expressed was that a major difference in the experience of patient death related to the lack of opportunity to correct mistakes when nursing a dying patient. The knowledge that 'it must be right first time' presents a real challenge to nursing skills as referred to by Katz (1996). The consequences of 'not getting it right' were linked to the repercussions for the patient/family as well as to the nurses' emotional responses to events.

Some nurses reported their perceived need to hide their emotions from their patients because showing their feelings might interfere with their ability to support the patient and/or family. This need to hold back the emotion is likely to increase the strain on emotional resources, which nurses in this sample say is created by any death. This may also be interpreted as nurses perceiving their emotional responses as a threat to their ability to carry out their work in accordance with their professional commitments. Data suggest that the experience of patient death appears to threaten or challenge professional and personal skills on both practical and emotional levels and therefore poses a risk to both professional and personal well-being in a way which may not be so evident with other sources of stress. McWilliam et al. (1993), in their in-depth studies of two palliative care nurses, reported a similar finding, in that the nurses experienced both internal and external conflicts which resulted from the challenges associated with patient death. Those nurses reported the need to work at the resolution of those conflicts to maintain their own personal and professional integrity.

It does appear that, during the experience of caring for the dying, there is a greater threat or challenge to emotional resources and emotional well-being than with many other sources of stress. Nurses' reports suggest that there may be a somewhat circular effect: a threat to emotional well-being may arise because of the emotional nature of death as well as the emotional response to not meeting professional commitments; a threat to professional aims and commitments (and professional well-being) may result from an inability to control emotional responses.

The majority of the qualitative data which related to this perceived difference in the stress associated with patient death referred to the difficult emotional issues. This may be an area where Briner's (1994) comment, that stress researchers should make more distinction between the affective states resulting from stress, would be appropriate. The reported

evidence, in this sample, that sadness is the main effect felt after a patient death (see Chapter Seven) may, in itself, signal an emotional response to patient death which is different from the emotional response to other stressors.

### Approach to Coping

The perceived difference between stress from patient death and stress from other sources may also be related to coping strategies perceived to be available to the nurse. Nurses may address the practical aspects of workplace stress through training and experience in very structured or tangible ways such as setting priorities, sharing workloads or using different procedures. Although nurses in this sample appear to recognise that patient death causes a different kind of reaction from other sources of stress, few nurses appear to have found or acknowledged specific ways to cope with patient death. It may be that situations which threaten or challenge one's emotional resources and well-being are approached in a less-structured way and coping strategies may be more difficult to recognise and apply. The practical implications of this will be discussed further in Chapter Eight.

### Effects of the Event

It appears that the effects of patient death, at least in some circumstances, may be particularly long-lasting. Some nurses said that they were unable to "turn off" stress associated with patient death and they were unable to "go home and forget about it". They are sometimes left with feelings of guilt or inadequacy and some deaths are never forgotten. These emotional responses seem to suggest outcomes or effects of these stressful events which may differ from the outcomes or effects of other stressors. What is likely is that those effects will impact on the appraisal process during future encounters with patient death.

Interestingly, one nurse commented that nurses are "*geared up to think about patient death differently*" (INT9-GEN). This appears to reflect a perception of being trained to think about patient death in a way which differs from how the nurse may think about other stressors. Such an idea raises the question of whether it would be possible to encourage nurses to think about patient death in specific ways which would be more beneficial in dealing with this work. Using the Lazarus and Folkman (1984) framework, this would be

an attempt to achieve a different outcome of the appraisal part of the stress process. For example, one might try to encourage the nurse to adopt/develop a particular perspective (or personal philosophy) about death and dying, or to be aware of and implement a wider range of coping strategies. This is an idea worthy of further research and will be discussed further in Chapter Eight.

#### 4.3.4 - Coping Strategies

The importance of social support, especially talking things over with colleagues, in coping with work-related stress supports the findings of other researchers (Vachon, 1987; Ceslowitz, 1989; Alexander and Ritchie, 1990; Boyle et al., 1991; Schaefer and Peterson, 1992). Tyler and Cushway (1992) also report that 61 percent of their sample expressed the wish to attend group support meetings, an indication of the perceived importance of social support in that sample of nurses.

The findings of this study raise several points related to coping. First, the benefits of working in teams which have an opportunity to develop close bonds between colleagues must be obvious. So, too, is the importance of maintaining good working relationships with other staff members and of improving communication among members and levels of staff. The changes in working practice in some units means that the nurses no longer leave the ward to have coffee breaks and some nurses in this sample recognised this change as a loss of opportunity to share worries with colleagues in a relaxed way. For those nurses who are unable to rely on family or friends outside of work, support from their colleagues was regarded as essential in times of trauma or crisis. This suggests that a more structured approach to insuring the availability of that support might be beneficial.

The fact that half of the 308 respondents said they used more than 2 coping strategies suggests that nurses have developed a range of coping resources. However, the data show that nurses use some coping strategies even though they realise that those strategies are not always very effective, a finding which is similar to that of Tyler and Cushway (1992). Only thirteen percent of this sample said they had any special ways of coping with patient death. This may show that nurses either do not develop event-specific coping responses or have little awareness of them. Alternatively, the finding may reflect a methodological weakness of the questionnaire method, wherein an individual may fail to include detailed

information in response to a particular question. A more extended interview to explore nursing/coping experiences may be more effective than a questionnaire approach in allowing the nurse, through reflection and discussion, to 'discover' and acknowledge his/her own coping strategies.

The overwhelming view of those interviewed was that stress associated with patient death differed from other work-related stress. If, as has been proposed, this difference is related to the amount of threat or challenge to the emotional resources and well-being, nurses need to find ways of increasing emotional resources and improving their ability to recognise and implement effective strategies to cope with emotional stressors. According to Lazarus and Folkman (1984), perceived ability to control a situation or to cope effectively with that situation is one of the most important factors in stress-appraisal. Increasing nurses' confidence in their ability to cope should reduce the potential for stress in this work. Indeed, as will be shown later, palliative care nurses in this sample, who have had greater training and experience, have higher scores on Coping with Death and Death Self-Efficacy and fewer of that group find patient death 'quite' or 'extremely' stressful (see Chapter Six).

The setting down and maintaining of limits or boundaries between home and work has also been reported by nurses to be an important coping strategy. For some nurses, though, there is a conflict between their understanding and expectation of the nursing role and their attempts to maintain the boundaries between home and work. Believing that it is important or even essential to 'get involved' with patients makes it difficult to separate nursing duties from personal obligations. The relationship may develop into a friendship which imposes obligations on a 'one human to another' basis, in addition to those felt on the nurse/patient basis. The obligations that the nurse feels are not restricted to the patient but extend to the families. This increases the risk that the nurse will identify with the patient's situation and become more involved. In theoretical terms, it is this kind of involvement which may threaten a nurse's emotional well-being in nursing and especially in caring for the dying. It is also this involvement which may make implementation of an effective coping strategy (the setting and maintaining of boundaries) more difficult.

Undoubtedly, the preference would be for nurses to remain caring and compassionate in their nursing role without becoming emotionally involved with the patient. Whether that is

possible is a moot point but, for those nurses who do 'get involved', it is important, as was said by one nurse, to 'get uninvolved after'. This may be a key coping skill. Perhaps training could help nurses to learn to recognise when and why they need to 'get uninvolved'. How to get 'uninvolved' would be a personal decision in the same way as coping strategies are. However, nurses might be encouraged to think about and develop their own personal plan or ritual for achieving this.

#### **4.4 - Summary**

As in previous literature, levels of reported stress, measured by the GHQ-12, do not differ significantly across groups of nurses. Where there is a difference on two of the three burnout elements (MBI), mean scores for the psychiatric nurses, who score highest, are still within the moderate range. The similarities between the results in this and other studies suggests that this sample of nurses does not exhibit unusually high levels of reported stress.

The data on sources of stress confirm previous findings in three ways. Workload and staffing levels continue to be reported by nurses as the most important sources of stress. Second, the importance of individual stressors varies as a function of clinical area of work, a finding which underlines the need to account for unit-specific needs when attempting to reduce stress. Finally, while patient death is not rated as the most important stressor, it is rated as a substantial source of stress.

Previous literature has made little distinction between the stress associated with patient death and that from any other stressor. However, the qualitative data in this study suggests that nurses perceive a difference which may be related to the emotional nature of the event which challenges both personal and professional capabilities, to their approach to coping with this event and/or effects of the experience.

Previous findings are also confirmed in the data on coping. Social support is again the most important coping resource reported by this sample of nurses who also report some difficulties with finding the kind of support which they need, when they need it. The data suggest that many nurses either do not have or are unaware that they use any specific coping strategy to deal with death and dying.



This section of the work has provided a contextual basis for the work which follows. In terms of levels and sources of stress, the sample of nurses appears to be very similar to those used in previous studies, and to that extent at least, may be seen as representative of the wider population of nurses. This is important, especially because of the exploratory nature of the remaining sections of this research.

Based on previous literature, one assumption underlying this study is that working with dying patients must have some effect on nurses and the findings in this chapter have confirmed that nurses do perceive their work to affect them in different ways. The next chapter will explore the issue of fear of death in nurses, and in a general population sample, to understand further how working with the dying affects nurses.

## CHAPTER FIVE

### **Results and Discussion: Fear of Death**

#### **5.1 - Introduction**

##### **5.1.1: Hypotheses**

Hypothesis a) Palliative care nurses will have lower levels of fear of death than the other two groups of nurses.

Hypothesis b) Scores on Fear of Death will be positively correlated with scores on GHQ-12 (indicating high levels of fear associated with low levels of psychological well-being).

Hypothesis c) 'Frequency of patient death experienced' will correlate negatively with levels of fear of death.

Hypothesis d) Nurses' levels of fear of death will be lower than those of the general population.

##### **5.1.2: Procedure**

The Fear of Death Scale (Howells, Gould & Field, 1986, see Appendix II) was used with the nursing sample and modified, to remove questions relating to dying patients, for use with the general population sample (see Chapter 2). This quantitative scale allowed statistical comparison across the three nursing groups and between nursing groups and the general population sample. Some information was also gathered from nurses' comments during interviews.

Because of the amount of data reported in the write-up below, in the interests of clarity and accessibility, some comment is offered in juxtaposition to findings, rather than in the main discussion section.

### 5.1.3: Data Analysis

Because the data did not show normal distribution, computer analyses used nonparametric statistical tests (see Chapter Two). Notwithstanding the usual need for a prudent approach to generalisation, the findings on 'fear of death' need to be treated with caution until the research can be replicated with other samples.

Several points relating to the two samples (nurses and general population) arose from demographic information on returned questionnaires. These factors were considered when analysing the data on Fear of Death. The first point concerned age breakdown within samples. The nursing sample included only persons 65 years or under, in contrast to the general population sample in which 13.3 percent were aged over 65. Gender was also a factor. Although both samples included males and females, the percentage of males in the general population sample was 35 percent while only 13.3 percent of the nursing sample were male and of those, it is significant that most were in the psychiatric nursing group where patient death is usually a less frequent occurrence. Further, 21 percent of the nursing sample, compared to 11 percent of the general population sample had suffered a personal bereavement during the previous 6 months. The 66 nurses who had suffered recent bereavement were almost equally spread across the three groups (Palliative - 22, Psychiatric - 25 and General - 19).

## 5.2 - Findings

### 5.2.1 - The Nursing Sample

#### 5.2.1.i - Fear of Death

Mean scores on the eight 'fear of death' questions are given in Table 5.1 for the overall sample and for each group of nurses. The highest score on levels of fear relates to fear of the death of a close other (FOD3), followed by fear of the process of death (FOD1). Highest scores on frequency of thought relate to imminent patient death (FOD8), followed by thoughts of death of a close other (FOD2) and then the process of one's own death (FOD5).

This pattern of highest/lowest mean scores for levels of fear within the whole sample is partly in line with other studies of medical students (Firth-Cozens and Field, 1991, Howells et al., 1986, Howells and Field, 1982). Medical students in the study carried out by Firth-Cozens and Field (1991) rated highest on fear associated with death of a close other, followed by own dying, talking to a dying patient and fear of being dead. However, nurses differ from the medical students in that they report more fear of being dead than of talking with their dying patient about his/her condition. One explanation for this may be found in the qualitative data which suggest that this is related to respondent interpretation of "being dead". During interviews, some nurses said they didn't fear for themselves once dead, but spoke of this in terms of children left behind, or the consequences for others of their being dead. Since many nurses are mothers, the importance of consequences for others, in the event of their death, would be considerable. It is impossible to assess differences between respondent interpretation of the question in this and other studies.

**Hypothesis a)** Palliative care nurses will have lower levels of fear of death than the other two groups of nurses.

Table 5.1 also shows where there are significant differences between groups. General nurses score significantly higher than the other two groups on fear associated with the death of a close other.

Table 5.1: Fear of Death in Nursing Sample -Means and Standard Deviations (SD)

|                        | Full Sample<br>n=301<br>Mean (SD) | Palliative<br>n=106 | Psychiatric<br>n=98 | General<br>n=97 | Kruskal-Wallis<br>Anova (groups)<br>Chi Square | 1-way |
|------------------------|-----------------------------------|---------------------|---------------------|-----------------|--|-------|
| FOD 1 -<br>own dying   | 4.34 (1.68)                       | 4.26 (1.67)         | 4.20 (1.63)         | 4.55 (1.74)     | NS   |       |
| FOD 2<br>being dead    | 3.34 (2.11)                       | 3.10 (2.10)         | 3.42 (2.11)         | 3.53 (2.13)     | NS   |       |
| FOD 3<br>close other   | 5.60 (1.48)                       | 5.46 (1.48)         | 5.47 (1.47)         | 5.87 (1.46)     | <b>7.88, DF 2, p&lt;0.02</b>                   |       |
| FOD 4<br>dying patient | 2.24 (1.28)                       | 1.67 (0.96)         | 2.71 (1.41)         | 2.39 (1.23)     | <b>38.19, DF2, p&lt;0.0001</b>                 |       |
| FOD 5<br>own dying     | 2.03 (1.01)                       | 2.32 (1.14)         | 1.87 (0.88)         | 1.87 (0.91)     | <b>10.66, DF2, p&lt;0.01</b>                   |       |
| FOD 6<br>being dead    | 1.78 (0.96)                       | 2.10 (1.21)         | 1.61 (0.78)         | 1.60 (0.83)     | <b>15.07, DF2, p&lt;0.001</b>                  |       |
| FOD 7<br>close other   | 2.43 (1.10)                       | 2.66 (1.14)         | 2.21 (1.04)         | 2.39 (1.07)     | <b>7.50, DF2, p&lt;0.05</b>                    |       |
| FOD 8<br>dying patient | 2.93 (1.37)                       | 3.78 (1.10)         | 1.99 (1.14)         | 2.95 (1.25)     | <b>87.80, DF2, p&lt;0.0001</b>                 |       |

NOTE FOD 1 to FOD 4 inc rated on scale of 1 to 7 - levels of fear  
FOD 5 to FOD 8 inc rated on scale of 1 to 5 - frequency of thought

Palliative/terminal care nurses score lowest on fear associated with talking to a dying patient, a result which may reflect a combination of greater experience and more specific training. This finding makes the hypothesis acceptable, in part only. As can be seen in Table 5.1, the results do not show palliative care nurses having fear of death scores significantly lower than both of the other two groups on all questions related to levels of fear (FOD1 to FOD4).

Palliative care nurses consistently score higher on frequency of thoughts about these concepts. This is not surprising considering the nature of their work. As will be discussed later, interview data revealed that, for some nurses, frequency of thought about one's own death did increase when the nurse was coping with very frequent patient death. However, it is noteworthy that, in this survey, palliative care nurses, although they encounter patient death more often, do not score significantly higher on any of the questions relating to levels of fear of death (FOD1 to FOD 4).

For nurses, frequency of thought is highest relating to dying patients (FOD 8), followed by thinking about the death of a close other (FOD 7). This is in contrast to the 4th year medical students, studied by Howells et al. (1986), who thought more frequently about death of a close other, and possibly reflects the nurses' greater frequency of working directly with the dying. If the question pertaining to patients is removed, the hierarchy of frequency is the same for nurses and medical students.

To summarise, the hypothesis is accepted only in part. Palliative nurses do report lower levels of fear than the other two groups in terms of fear associated with talking to dying patients, but in terms of fear of the death of a close other, palliative mean scores do not differ significantly from those of psychiatric nurses and general nurses' mean scores are significantly higher than both palliative and psychiatric nurses. Palliative nurses score significantly higher on all frequency of thought questions (FOD 5 to FOD 8).

### 5.2.1.ii- Fear of Death and GHQ-12

**Hypothesis b)** Scores on Fear of Death will be positively correlated with scores on GHQ-12 (indicating high levels of fear associated with low levels of psychological well-being).

As seen in Table 5.2, there were very low but significant positive correlations (Spearman) between GHQ-12 scores and scores on some Fear of Death questions, indicating that high levels of fear of death correlate with low levels of well-being. Significant correlations are seen on levels of fear of death relating to one's own dying (FOD1), death of a loved one (FOD3) and frequency of thought about being dead (FOD6) and about death of a loved one (FOD7). Firth-Cozens and Field (1991), in their study of medical students, found GHQ to be related only to levels of fear of someone close dying (they did not investigate frequency of thought). However, general psychological health is considered to be one of the main determinants of death anxiety and depression has been shown to be positively correlated with death anxiety (Lonetto, 1986).

Table 5.2: Spearman Correlations for GHQ-12 and Fear of Death - Nursing Sample

|        | FOD 1<br>(levels)<br>own dying | FOD 2<br>being<br>dead | FOD 3<br>close<br>other    | FOD 4<br>dying<br>patient | FOD 5<br>(freq'y)<br>own dying | FOD 6<br>being<br>dead     | FOD 7<br>close<br>other    | FOD 8<br>dying<br>patient |
|--------|--------------------------------|------------------------|----------------------------|---------------------------|--------------------------------|----------------------------|----------------------------|---------------------------|
| GHQ-12 | 0.1986<br><b>Sig 0.001</b>     | 0.0747<br>Sig 0.200    | 0.1407<br><b>Sig 0.015</b> | 0.0796<br>Sig 0.172       | 0.1130<br>Sig 0.052            | 0.1651<br><b>Sig 0.004</b> | 0.2169<br><b>Sig 0.000</b> | 0.0923<br>Sig 0.113       |

Additional evidence of this relationship is found when the whole nursing sample is divided on the basis of GHQ-12 threshold scores above three and equal to or lower than three (to establish 'caseness'). Mann-Whitney tests indicate a significant ( $p < 0.02$ ) difference between the groups on the same four fear of death questions, FOD1, FOD3, FOD6 and FOD7. Thus the hypothesis that there will be a positive relationship between scores on GHQ-12 and Fear of Death scores is accepted (indicating that high levels of fear are associated with low levels of well-being) whilst noting that the level of association remains small in all cases.

### 5.2.1.iii - Age and 'Frequency of Patient Death Experienced' as Correlates of Fear of Death

Table 5.3 shows Spearman correlation coefficients for relationships between fear of death questions (FOD1 to FOD8), age, and frequency of patient death experienced (FRDEA), using scores from the whole nursing sample. The SPSS for Windows analysis software includes correction for ties where necessary when using the Spearman test (Norusis, 1993).

Hypothesis c) 'Frequency of patient death experienced' will correlate negatively with levels of fear of death.

Table 5.3: Correlations - Age, Frequency of patient death experienced (FRDEA) and Fear of Death (FOD 1 to 8) - Spearman Correlation Coefficients - Nursing Sample

|                          | AGE                     | FRDEA                   | FOD1                   | FOD2                   | FOD3                   | FOD4                    | FOD5                   | FOD6                   | FOD7                   |
|--------------------------|-------------------------|-------------------------|------------------------|------------------------|------------------------|-------------------------|------------------------|------------------------|------------------------|
| FRDEA                    | -0.0319<br>Sig<br>0.578 |                         |                        |                        |                        |                         |                        |                        |                        |
| FOD1<br>own<br>dying     | -0.1904<br>Sig<br>0.001 | -0.1243<br>Sig<br>0.031 |                        |                        |                        |                         |                        |                        |                        |
| FOD2<br>being<br>dead    | -0.0958<br>Sig<br>0.097 | -0.1891<br>Sig<br>0.001 | 0.5884<br>Sig<br>0.000 |                        |                        |                         |                        |                        |                        |
| FOD3<br>close<br>other   | -0.1943<br>Sig<br>0.001 | -0.0955<br>Sig<br>0.098 | 0.4380<br>Sig<br>0.000 | 0.3858<br>Sig<br>0.000 |                        |                         |                        |                        |                        |
| FOD4<br>dying<br>patient | -0.1840<br>Sig<br>0.001 | -0.3228<br>Sig<br>0.000 | 0.1969<br>Sig<br>0.001 | 0.1738<br>Sig<br>0.002 | 0.2293<br>Sig<br>0.000 |                         |                        |                        |                        |
| FOD5<br>own<br>dying     | 0.0602<br>Sig<br>0.298  | 0.0915<br>Sig<br>0.113  | 0.1707<br>Sig<br>0.003 | 0.1562<br>Sig<br>0.007 | 0.646<br>Sig<br>0.264  | -0.0625<br>Sig<br>0.280 |                        |                        |                        |
| FOD6<br>being<br>dead    | 0.0578<br>Sig<br>0.318  | 0.1215<br>Sig<br>0.035  | 0.1566<br>Sig<br>0.007 | 0.1513<br>Sig<br>0.009 | 0.0732<br>Sig<br>0.206 | 0.0015<br>Sig<br>0.980  | 0.6952<br>Sig<br>0.000 |                        |                        |
| FOD7<br>close<br>other   | 0.0442<br>Sig<br>0.445  | 0.0800<br>Sig<br>0.166  | 0.1481<br>Sig<br>0.010 | 0.0882<br>Sig<br>0.127 | 0.2377<br>Sig<br>0.000 | 0.1397<br>Sig<br>0.015  | 0.3419<br>Sig<br>0.000 | 0.4451<br>Sig<br>0.000 |                        |
| FOD8<br>patient<br>death | 0.1503<br>Sig<br>0.009  | 0.4364<br>Sig<br>0.000  | 0.0448<br>Sig<br>0.439 | 0.0039<br>Sig<br>0.946 | 0.0150<br>Sig<br>0.796 | -0.2244<br>Sig<br>0.000 | 0.2962<br>Sig<br>0.000 | 0.2863<br>Sig<br>0.000 | 0.2000<br>Sig<br>0.000 |

Note: FOD1 to FOD4 - levels of fear associated with own dying, etc,  
FOD5 to FOD8 - frequency of thought about own dying, etc

Where there are small but significant correlations, both age and frequency of patient death experienced (FRDEA) correlate negatively with levels of fear (FOD1 to FOD4). Thus the hypothesis is accepted. However, correlations between age and frequency of patient death

and frequency of thought (FOD5 to FOD8) scores are positive (though not always significant).

Previous studies using the same measure of fear of death have investigated groups where age differences were negligible (medical students in the same cohort). However, previous research on death anxiety, by Templer et. al. (1971), showed no significant relationship between age and death anxiety in five large samples ranging in size from 115 to 1271 and drawn from different populations which included some adolescents, parents of those adolescents, residents of an apartment block, psychiatric patients and a group of low-income psychiatric aides. In this nursing sample, it is possible that the important factor in the correlation between age and fear of death may be the experience which comes with age in the profession. Older nurses are more common among the palliative care group who deal with death and dying patients on a daily basis and are thus more experienced. It is unfortunate that multivariate statistical tests were ruled out by the skewed nature of the data, making it impossible to separate out the effects of the two variables. The importance of age as opposed to experience associated with death is a question which may be addressed in future research.

#### 5.2.1.iv - Other Factors

There was no significant difference on either levels or frequency, on Fear of Death questions, between those nurses who had /had not been recently bereaved (Mann-Whitney U), or between those who said they did /did not have a religious faith. The Mann-Whitney U test indicates a significant difference based on gender with females scoring higher on fear associated with thoughts of death of a close other ( $p<0.0001$ ) and on frequency of thought about patient death ( $p<0.0001$ ). However, it should be noted that most of the males in this sample are in psychiatric nursing where patient death is experienced relatively infrequently.

There was a significant difference in fear of death scores between those who had or had not had extra training related to palliative care and/or caring for the dying patient and/or bereavement counselling ( using Mann-Whitney U, FOD1 -  $p<0.005$ , FOD2 -  $p<0.02$ , FOD3 -  $p<0.05$ , FOD4 -  $p<0.0001$ ). Those having extra training in some or all of those aspects reported lower levels of fear.



Although correlation statistics show significant coefficients between frequency of thought scores and intensity of fear scores, those coefficients are very small, the largest being 0.2377 between frequency of thought (FOD7) and intensity of fear (FOD3) associated with thoughts about death of a close other (see Table 5.3).

#### 5.2.1.v - Qualitative Findings

While the issue of fear of death was investigated primarily through the use of the quantitative measure, qualitative data proved to be useful in suggesting tentative explanations for some of the quantitative findings as shown above in 5.2.1.i, as well as some additional comment on fear of death.

Some nurses who were interviewed said that their own fear of dying was increased when they experienced many deaths in a short time, and when they identified with a particular patient, especially if the patient was of a similar age to the nurse. The fear related to the process of dying and whether their own death would be a 'good death' of the kind which they attempt to produce for their patients. This fear apparently relates not just to the actual process of death but to the period of illness which causes the death. Several nurses expressed personal fears and concerns which were related to caring for patients with particular diseases (for example motor neurone disease) for which there is perceived to be a poorer range of symptom-control methods (compared with, for example cancer). As one nurse said *"Doctors can do so much for some things"* (INT 25- Pall).

#### 5.2.1.vi - Summary

To summarise, there are differences, across the three nursing groups, on some of the fear of death questions. Most notably, palliative care nurses do score lower on levels of fear associated with nursing the dying patient and general nurses score higher on fear associated with the death of a close other. Palliative care nurses score higher on all frequency of thought questions. Psychological health (GHQ-12), age and frequency of patient death are all shown as correlates of fear of death, though coefficients are generally small.

### 5.2.2 - General Population Sample

#### 5.2.2.i - Fear of Death

In the general population sample, the mean scores (shown in Table 5.5) showed the same

Table 5.5: Mean Scores and Standard Deviation for levels of Fear of Death - General Population Sample (n=430)

|   | Mean Score (Standard Deviation) |
|---|---------------------------------|
| FOD 1 - level of fear of own dying            | 3.57 (1.94)                     |
| FOD 2 - level of fear of being dead           | 2.94 (2.09)                     |
| FOD 3 - level of fear of death of close other | 5.44 (1.81)                     |

pattern as in the nursing sample, i.e. highest for fear of death of a close other, followed by fear of the process of dying and fear of being dead.

#### 5.2.2.ii- Age and Gender

Using the whole sample, there were small but significant negative correlations (Spearman's) between age and fear of process of death ( $-0.1021$ ,  $p<0.05$ ), fear of being dead ( $-0.1381$ ,  $p<0.01$ ) and fear of death of a close other ( $-0.0962$ ,  $p<0.05$ ). Using only the sample aged 65 or under to match with the nursing sample, age does not correlate significantly with any of the three fear ratings. Differences based on gender do appear in the general population sample. Mann-Whitney U indicates that females score higher ( $p<0.001$ ) on fear of process of dying (FOD1) and death of close other (FOD3) and higher ( $p<0.02$ ) on fear of being dead (FOD2).

#### 5.2.2.iii - Other Factors

In the general population sample, no significant differences were found between scores for those who were/were not recently bereaved.

### 5.2.3 - Comparison of Nurses and General Population

Hypothesis d) Nurses' levels of fear of death will be lower than those of the general population.

Both samples (nurses and general population) were filtered to compare only females 18 - 65 years of age to eliminate the gender factor and control for the age factor. Table 5.6 shows comparisons between nurses and the general population sample for scores on the three aspects of fear of death (FOD 1 to FOD3). Nurses score significantly higher ( $p<0.004$ ) than the general population on the fear associated with the process of one's own dying (FOD1). When only males aged 65 years and under from both samples are compared (not shown in the table), the nursing sample still scores higher ( $p<0.03$ ) on fear associated with the process of dying (FOD1). However, it must be remembered that this sample of male nurses is a very specialist group.

Using only females 65 years or under from the two samples, and comparing individual nursing groups with the general population sample, palliative care nurses score significantly lower than the general population on fear of death of a close other (FOD 3,  $p<0.03$ ) and general nurses score significantly higher on fear of the process of dying (FOD 1,  $p<0.01$ ).

Table 5.6: Fear of Death (FOD 1 - 3) comparing mean scores of nurses and general population sample (GP)

|             | Males and Females<br>18 - 65 yr<br>Nurses (n=308)<br>GP (n=373) | Significant<br>differences<br><br>Mann-Whitney U | Females only<br>18 - 65 yr<br>Nurses (n=260)<br>GP (n=248) | Significant<br>differences<br><br>Mann-Whitney U |
|-------------|---|--|--|--|
| FOD1 nurses | 4.34 (SD 1.68)  | $p<0.0001$                                       | 4.39 (SD 1.69)   | $p<0.004$  |
| FOD1 GP     | 3.68 (SD 1.91)  |  | 3.90 (SD 1.85)   |  |
| FOD2 nurses | 3.34 (SD 2.11)  | NS   | 3.42 (SD 2.16)   | NS   |
| FOD2 GP     | 3.06 (SD 2.12)  |  | 3.21 (SD 2.14)   |  |
| FOD3 nurses | 5.60 (SD 1.48)  | NS   | 5.75 (SD 1.36)   | NS   |
| FOD3 GP     | 5.57 (SD 1.64)  |  | 5.79 (SD 1.51)   |  |

FOD1 - fear associated with process of one's own dying

FOD2 - fear associated with being dead

FOD3 - fear associated with death of a close other

Although the results differ across the three fear of death questions and across the nursing groups, the hypothesis that nurses will score lower on fear of death questions must be rejected. There is no previous research with which to compare these results. These findings are very significant and, while there is a very real need for further research to attempt to replicate the results, the findings suggest that nurses' work may have an important effect on their fears about death and dying issues. Furthermore, the specific nature of the nursing work may be an important factor, since there are some group differences in the comparison of nurses' scores with the general population sample.

### **5.3 - Discussion**

The idea that some element of nursing work may influence nurses' personal fears associated with death and dying is supported by these results which show some significant differences in Fear of Death scores across the three nursing groups and between nurses and the general population sample.

Psychiatric nurses in this sample experienced significantly fewer patient deaths than either general or palliative nurses and report levels of fear which do not differ significantly from the public. General nurses experience patient death significantly more than psychiatric and less than palliative nurses and report levels of fear of some aspects which are very significantly higher than the general public. However, palliative care nurses experience very frequent patient death, higher than the other two groups, yet report significantly lower levels of fear of some aspects than other nurses and than the general public. The question is why? Two possible reasons may be proposed and both may have a role to play. It is possible that those nurses who enter palliative care nursing are those who have less fear of death and dying. Secondly, previous research (Howells et. al., 1986; Firth-Cozens and Field, 1991) and these findings suggest that the training for, and experience of, caring for many dying patients may have some effect on levels of fear.

Further research is required to address the first possibility. The second possibility is supported, in part, by the lower scores on fear of death questions for those nurses who had extra training to deal with death, dying and bereavement issues (5.2.1.iv). Within the nursing sample, a strong factor (though not necessarily the only important factor) in

reducing palliative care nurses' fear of discussion with a dying patient is likely to be their greater experience and training in this regard.

The negative correlation between frequency of patient death experienced (FRDEA) and levels of fear, especially fear associated with talking to dying patients (FOD 4), supports the contention, made earlier by Firth-Cozens and Field (1991), that experience of death and dying may reduce levels of fear. However, this does not explain why general nurses show higher levels of fear of the process of dying when they experience patient death more frequently than psychiatric nurses and more frequently than the general population. This contradiction in findings emphasises the complexity of death attitudes and the need for further research.

Notwithstanding the need for further investigation, these results give rise to the possibility that the relationship between experience of death and dying and levels of fear of death either follows a pattern similar to the inverted-U or fits a cut-off or threshold model. That is, fear of death may be increased by each experience of patient death up to a point where the nurse feels more able to cope with death and begins to experience a reduction in fear (as in an inverted-U). A cut-off or threshold model would suggest that fear of death increased with each experience to a maximum level of fear, at which the increase in fear stops and the level of fear then remains stable or decreases.

Whether a nurse would ever approach a patient's death without any fear is a moot point, but the reduction in fear may continue for some period of time during which several death-related experiences occur. It may be that when nurses experience very frequent death, cope with that experience and possibly witness a variety of dying experiences which includes 'good death', their fears are lowered. Bandura's (1977) social learning theory proposes that we gain confidence in our ability to do things by having done them before, but we also learn by watching others do things and gain confidence from seeing that others do things successfully. We only have one 'opportunity' to experience our own dying but there is evidence from nurses in this study that patients in hospices who see others die peacefully and pain-free are relieved and appear to fear their own death less. This is in line with research by Honeybun et al. (1992) and Payne et al. (1996) who found that hospice patients who witnessed other deaths benefited from their experience. If patients can benefit

in this way, then it is highly likely that nurses can too. One nurse indicated that this may be possible:

*"It is comforting to see someone make the transition between life and death in a peaceful manner and makes me hope my own death will be as untroubled." (D 11-PALL)*

A poignant note, written by a member of the public on their returned Fear of Death survey questionnaire, also supports this idea.

*"This (fear associated with the thought of being dead) has changed since losing my sister. Before, it (marked as scoring 2) would have been at least 7. This (thought of someone close to you dying) again has changed. Now everyday I live with my heart in my mouth. PS- I think losing my sister quite suddenly in a car accident has made me feel that it won't be so terrifying when I die as she's done it already and paved the way (I can't really explain it any better)" (GP survey #407)*

General nurses score higher than the other two nursing groups on fear associated with the death of a close other. This finding may be related to real or perceived differences in nursing practice between palliative and general nursing areas. There was clear evidence from qualitative data that there is a perception, held by both palliative and general care nurses, that the event of patient death is generally handled more effectively in palliative units (see also Fisher, 1991). Some nurses stated their reason for working in palliative care nursing was because they believed that care of the dying was inadequate in general nursing units and that they could give better care in palliative units. One nurse explained:

*"...I was just looking for anything...and this ( a job in a hospice) was advertised...ooh, I'm applying for that. And I was able to give...cause I never felt that what I'd been trained to do, I was able to deliver on an ordinary general ward." (INT 4-PALL).*

This may mean that general nurses have less confidence about care available to dying loved ones. Because general nurses also tend to see the serious illness and/or death of a greater range of ages and from a wider range of causes, they may also perceive a greater number of threats to loved ones. That being so, both factors may increase levels of fear associated with thinking about the death of a close other.

The higher scores for palliative nurses on frequency of thought questions suggest that clinical experience of death and dying may increase the frequency of thought about these concepts. This result supports the findings of Howells et al. (1986) who studied medical students. The low correlation coefficients between intensity and frequency scores provide very limited evidence from this study that the increased frequency of thought is related to increased fear. It is worth noting, however, that the direction of these small but significant correlations is generally positive, with the exception of that between fear of talking with the dying patient (FOD4) and frequency of thought about dying patients (FOD8), which is negative. This requires further investigation, but may indicate a difference between death attitudes/fears about patients and attitudes pertaining to self or family.

Two methodological issues have arisen from the use of the Fear of Death Scale. The first of these relates to the meaning of questions as read by respondents and emphasises the value of qualitative investigation when dealing with emotional issues. During interviews, nurses spoke of the fears associated with their 'being dead'. These fears were really about the repercussions, for others, of the nurse being dead, while Howells et al. (1986) were intending to measure the individual's fear of the state of being dead. This underlines the necessity for some further thought on wording of questions in such a scale to ensure that all respondents will read the same meaning into each question.

Secondly, the rationale of Howells et al. (1986) for using questions about both levels of fear and frequency of thought was that "trait fearfulness is a product of both the intensity of fear and of the frequency with which fearful reactions arise" (p503). The use of these frequency questions in this scale seems to imply that every thought about death and dying would be a fearful thought. However, it can be argued that a person may have thoughts about the process of their own dying which would not be fearful. This may be especially true of someone who is trained to work with the dying, has experienced the death of others and more especially, has experience of what is perceived as 'a good death'. This idea is supported by the finding that, although palliative nurses score significantly higher than other nurses on frequency of thought questions, they do not score higher on levels of fear and they score lower than the general population sample on fear associated with the death of a close other. Further, all correlations between frequency of patient death

experienced (FRDEA) and levels of fear questions (FOD 1 to FOD 4), though small, are negative.

It would appear that clinical experience may cause one to think more frequently about death and dying issues, but in doing so, one increases in confidence and, in time, reduces levels of fear associated with these issues. However, it would also appear that until a nurse reaches a certain level of experience of death and dying situations and gains certain levels of confidence, s/he may be suffering increased levels of fear associated with death and dying. If Cundey (1981) was right in the assertion that nurses may project their personal fears onto their patients, there are implications for patient care as well as for the well-being of the nurse.

The incidence of recent bereavement would appear to be high among both nursing and general population samples (21 percent of nurses and 11 percent of the general population). It is difficult to assess what effect, if any, this had on responses. Although anecdotal evidence would suggest that being recently bereaved would affect frequency of thought about death and dying, and may even influence fear of death, findings from this study do not support that view. However, a more accurate assessment of this would require a longitudinal study to find change within the individual, rather than a comparison of two groups, i.e. those who had and had not been recently bereaved (as in this study).

#### **5.4 - Summary**

This new work has resulted in findings which show that within the nursing sample there are some differences in scores on fear of death questions. Palliative care nurses, unsurprisingly, score highest on the frequencies with which they think about their own dying, the death of a close other, being dead, and the death of a patient. However, they score significantly lower on the level of fear associated with the dying patient. General nurses score significantly higher than the other two groups on the fear associated with the death of a close other.

This unique study of fear of death within a general population sample provides a base line against which nurses' scores on fear of death may be studied. While it is important that the research be replicated to confirm reliability of the results, these important new findings



indicate that general nurses report higher levels of fear associated with some aspects of death, palliative care nurses report lower levels of fear on some aspects and psychiatric nurses report levels similar to those of the general population. Previous research which concluded that clinical experience of death may reduce fear is not wholly supported in this study. These new findings suggest that increased fear may be associated with certain levels of clinical experience and reduced fear may be associated with even greater clinical experience.

Both nurses and the general population report more fear associated with the death of a close other than with their own death, a finding which supports the previous work with medical students. Further, the result that there is a very small but significant correlation between low levels of psychological well-being (GHQ) and some aspects of fear of death is in line with previous work on both fear of death and death anxiety.

Nurses who had extra training, related to caring for dying patients and their relatives, reported lower fear of death than those without extra training. Both age and the frequency of patient death experienced correlate negatively (with very small coefficients) with fear of death. The correlations between age and fear of death are in contrast to the previous work by Templer et al. (1971) on death anxiety, where no correlation was found within very large and varied population samples. The combined findings suggest that a likely explanation for this difference is that the training and work experience which nurses gain with increasing age is the important element, rather than age, per se.

The importance of research into death attitudes among those who care for the dying has been highlighted by the findings in this study. It appears that nurses' personal fears may well be affected by working with their dying patients. It is essential that these effects are recognised and that nurses are helped to cope in the most effective way possible. The next chapter will report findings related to coping with death and dying and will relate nurses' perceptions of their experiences of nursing the dying.

## **CHAPTER SIX**

### **Results and Discussion: Coping With Death and Caring For the Dying**

#### **6.1 - Introduction**

##### **6.1.1 - Hypotheses and Research Questions**

**Hypothesis a)** Palliative care nurses will have higher scores than the other two groups on Coping With Death and on Death Self-Efficacy.

**Hypothesis b)** Scores on Coping with Death and Death Self-Efficacy will be inversely related to scores on Fear of Death.

**Hypothesis c)** Scores on Coping with Death and Death Self-Efficacy will be inversely related to scores on GHQ-12.

**Question a)** Do nurses perceive their training to have been adequate for communicating with and caring for the dying, coping with relatives of the dying and dealing with their own feelings about patient death?

**Question b)** Which elements of caring for the dying and of patient death create the greatest potential for an appraisal of stress and negative effect on the nurse?

##### **6.1.2 - Procedure**

The hypotheses were addressed through the use of two further quantitative measures. The Coping with Death Scale (Bugen, 1980-1981), which addresses skills required to work in hospice care, was considered appropriate because skills required to work in hospice are primarily those required to care for the dying. The Death Self-Efficacy Scale (Robbins, 1992) addresses those skills required to work in terminal care as well as a range of skills needed to cope with personal bereavement and death-preparation behaviour. These quantitative measures allowed statistical comparison across the three groups of nurses. In addition, material from interviews and diaries was used to answer the research question where the aim was to find and report nurses' perceptions of their experiences of caring for

the dying. Some data from questions 10 and 18 on the questionnaire (Appendix IIb) also provided information about how nurses coped with death and dying.

### 6.1.3 - Data Analysis

Nonparametric statistical tests were used to analyse quantitative data because the data did not demonstrate normal distribution (see Chapter Two). Data on total scores for both measures were negatively skewed (Coping with Death = -0.198, standard error 0.140, Death Self-Efficacy = -0.388, standard error 0.141, using skewness statistics from SPSS Explore/descriptives menu). As previously stated, this suggests a need for caution in generalisation of the findings. While intuition suggests to the author that the skewed nature of the data may be a common pattern in the research on death attitudes, reports in the literature do not make this clear.

In order to investigate similarities in the two scales, separate exploratory factor analyses (varimax, seeking factors having eigenvalues greater than one) were carried out on data from Coping with Death and Death Self-Efficacy measures (see Chapter Two). The item content of the two sets of factors was compared to determine whether there is sufficient overlap in content of the two scales to suggest the necessity for development of a single, more efficient measure. Sample size is adequate for factor analysis of these two scales as there are at least six times as many subjects as variables (Child, 1990, Polit, 1996).

All tapes from interviews were listened to and transcriptions were made as part of a process similar to analytic induction (Bryman and Burgess, 1994). Having interviewed 25 nurses and read the 11 diaries, the researcher had formed 'impressions' of certain aspects of the data. These impressions were clarified or corrected as the interview tapes were heard and data organised under headings or categories. It was decided that the three categories of 'what happens prior to death', 'the event of patient death' and 'what happens after patient death' would provide a useful structure around which to organise these data. It was necessary to listen to some tapes several times to clarify meanings, to check accuracy of the researcher's perception of the data, to assess the relative importance of some statements and to look for contradiction. See 2.3.2 for a full discussion of qualitative data analysis.

For the benefit of the reader, the quantitative and qualitative findings are reported separately, each followed in turn by the relevant discussion.

## **6.2 - Quantitative Findings**

### **6.2.1 - Coping with Death and Death Self-Efficacy**

Both the Coping with Death and Death Self-Efficacy scales demonstrate good internal consistency (using Cronbach's,  $\alpha = 0.91$  and  $\alpha = 0.93$  respectively, and Guttman Split-half, 0.90 and 0.93 respectively). The correlation coefficient for the relationship between coping with death and death self-efficacy is 0.72 which would suggest that there may be considerable overlap in the two scales.

**Hypothesis a)** Palliative care nurses will have higher scores on Coping With Death and on Death Self-Efficacy.

Table 6.1: Coping with Death and Death Self-Efficacy - Means, Standard Deviations (SD) and Significant Differences (Sig diff) - Nursing Sample from three Clinical Areas

|  | Overall                                   | Palliative  | Psychiatric   | General   |
|--|---|---|---|---|
| Coping with Death<br>Total Mean (SD)   | 135.17 (26.76)                            | 145.83 (23.32)  | 132.59 (26.34)  | 126.36 (27.0)   |
| Sig diff                               | Chi Sq 28.58 (DF 2)<br><b>p&lt;0.0001</b> | Pall/Psy <b>p&lt;0.001</b><br>Pall/Gen <b>p&lt;0.0001</b> | Psy/Gen NS<br>Psy/Pall <b>p&lt;0.001</b>              | Gen/Psy NS<br>Gen/Pall <b>p&lt;0.0001</b>               |
| Death Self-Efficacy<br>Total Mean (SD) | 315.78 (53.69)                            | 331.86 (44.75)  | 314.28 (57.86)  | 299.52 (53.83)  |
| Sig diff                               | Chi Sq 17.78 (DF2)<br><b>p&lt;0.0001</b>  | Pall/Psy <b>p&lt;0.05</b><br>Pall/Gen <b>p&lt;0.0001</b>  | Psy/Gen <b>p&lt;0.05</b><br>Psy/Pall <b>p&lt;0.05</b> | Gen/Psy <b>p&lt;0.05</b><br>Gen/Pall <b>p&lt;0.0001</b> |

Note: Differences over 3 groups - Kruskal-Wallis 1-way Anova, over 2 groups - Mann-Whitney

Table 6.1 shows the mean scores, standard deviations and group comparisons for these two questionnaires. As would be expected, palliative care nurses scored significantly higher than the other two groups on both of these scales. The hypothesis is therefore accepted. General nurses score significantly lower than psychiatric nurses on death self-efficacy though not significantly different on coping with death.

### 6.2.2 - Coping with Death, Death Self-Efficacy and Fear of Death

Hypothesis b) Scores on Death Self-Efficacy and Coping with Death will be inversely related to scores on Fear of Death.

The Coping with Death Scale is intended to measure the competencies required to work with the dying while the Death Self-Efficacy Scale is intended to measure a broader range of skills related to caring for the dying as well as those related to death and dying issues in one's personal life.

There are significant negative correlations between scores on both Coping with Death and Death Self-Efficacy measures and all four questions about intensity of Fear of Death (FOD1 to FOD4) as is seen in Table 6.2. The level of correlation is substantial, indicating quite strong relationships between these variables. Thus the hypothesis is accepted. This important finding suggests that fear of dying and fear of loved ones dying may be reduced when one is knowledgeable and competent to handle a wide variety of issues and situations involving death and dying.

Table 6.2: Spearman Correlations: Fear of Death (FOD1 to 4), Coping with Death total (CDTOT) and Death Self-Efficacy total (DSETOT)

|                       | CDTOT (Coping with Death total) | DSETOT (Death Self-Efficacy total) |
|-----------------------|---------------------------------|------------------------------------|
| DSETOT                | 0.7205<br><b>Sig 0.000</b>      |                                    |
| FOD1<br>own dying     | -0.4517<br><b>Sig 0.000</b>     | -0.3819<br><b>Sig 0.000</b>        |
| FOD2<br>being dead    | -0.4195<br><b>Sig 0.000</b>     | -0.2934<br><b>Sig 0.000</b>        |
| FOD3<br>close other   | -0.3390<br><b>Sig 0.000</b>     | -0.3356<br><b>Sig 0.000</b>        |
| FOD4<br>dying patient | -0.4383<br><b>Sig 0.000</b>     | -0.3551<br><b>Sig 0.000</b>        |

### 6.2.3 - Coping with Death, Death Self-Efficacy and GHQ-12

Hypothesis c) Scores on Coping with Death and Death Self-Efficacy will be inversely related with scores on GHQ-12.

Death anxiety has been shown to be correlated with general psychological wellbeing (Lonetto, 1986). In this study, GHQ-12, which is a measure of psychological wellbeing,

has been shown to be negatively correlated with fear of death and fear of death has been shown to be negatively correlated with both Coping with Death and Death Self-Efficacy. Therefore, it is reasonable to expect that there may be a negative correlation between GHQ-12 and Coping with Death and Death Self-Efficacy.

Table 6.3 shows that significant negative correlations (Spearman) between GHQ-12 and Coping with Death and Death Self-Efficacy do exist although the coefficients are small.

Table 6.3: Correlations - GHQ-12, Coping With Death and Death Self-Efficacy - Whole Nursing Sample

|              | Coping With Death Total | Death Self-Efficacy Total |
|--------------|-------------------------|---------------------------|
| GHQ-12 Total | -0.1315 Sig 0.023       | -0.1766 Sig 0.002         |

The sample was split into those having GHQ-12 scores of three or less and those scoring higher than three (the threshold scoring method - see 2.2.2.iii, 3). Using Mann-Whitney, a significant difference was found on Death Self-Efficacy scores ( $p < .049$ ), with those having higher GHQ-12 scores reporting lower death self-efficacy. However, no significant difference was shown on Coping with Death scores. Therefore, the hypothesis that there is an inverse relationship between GHQ-12 and these two scales is accepted. However, the relationship appears to be relatively weak, especially in terms of Coping with Death.

#### 6.2.4 - Adequacy of Training for Specific Aspects of Terminal Care

Question a) Do nurses perceive their training to have been adequate for communicating with and caring for the dying, coping with relatives of the dying and dealing with their own feelings about patient death?

Table 6.4: Adequacy of training for Specific Aspects of Terminal Care

|                      | Communicating with and caring for the dying |    | Coping with relatives of the dying patient |    | Dealing with one's own feelings about patient death |    |
|----------------------|---|----|--|----|---|----|
|                      | YES   | NO | YES  | NO | YES   | NO |
| Palliative - Number  | 81  | 27 | 69   | 39 | 67  | 41 |
| % Group              | 75  | 25 | 64   | 36 | 62  | 38 |
| % Total              | 27  | 9  | 23   | 13 | 22  | 14 |
| Psychiatric - Number | 46  | 50 | 43   | 53 | 49  | 48 |
| % Group              | 48  | 52 | 45   | 55 | 51  | 49 |
| % Total              | 15  | 17 | 14   | 18 | 16  | 16 |
| General - Number     | 39  | 56 | 33   | 62 | 28  | 67 |
| % Group              | 41  | 59 | 35   | 65 | 30  | 70 |
| % Total              | 13  | 19 | 11   | 21 | 9   | 22 |

Table 6.4 shows responses from the nursing groups to question 10 from the questionnaire, (Appendix IIb), about whether their training has adequately prepared them for communicating with and caring for the dying, coping with relatives of the dying and dealing with their own feelings about patient death. While palliative care nurses appear to feel more confident in this regard, general nurses appear to feel least prepared by their training.

Nevertheless, 25 percent of the palliative group still say that their training was inadequate to prepare them for communicating with and caring for the dying, 36 percent feel that they were inadequately trained to deal with relatives and 38 percent feel that their training did not prepare them adequately to cope with their own feelings about patient death. Caring for relatives was frequently said to be the most challenging aspect of the work because of emotional intensity and the infinite variety in people's reactions to bereavement.

The role of training is highlighted in the finding that there was a significant difference in perceived coping abilities (Coping with Death - CD and Death Self-Efficacy - DSE) between those of the sample who had or had not had extra training in palliative care and/or caring for the dying patient and/or bereavement counselling (using Mann-Whitney U, CD -  $p < 0.0001$ , DSE -  $p < 0.01$ ). Those having extra training reported higher levels of perceived coping ability or self-efficacy.

### **6.3 - Discussion (Quantitative Data)**

#### **6.3.1 - The Instruments**

The reliability statistics reported above for the two scales advance the work of Robbins (1992) insofar as they show that both scales have good internal consistency. However, exploratory factor analyses on the scales for Coping with Death and Death Self-Efficacy revealed some similarity in content of the factors in the two scales. In each case, the factors accounting for the largest portion of the variance relate to 'the ability to communicate with, listen to and provide emotional support for the dying patient and their family' and each scale contains a factor relating to 'coping with personal bereavements' (see Appendices VI and VII). The results of these factor analyses suggest that, in future research, a more efficient scale could be devised using the highest loading items from the

two scales. Such a scale would be intended to measure perceived ability to cope with a range of death and dying issues pertaining to caring for a dying patient as well as those skills required to deal with personal loss and one's own death-preparation behaviours (such as writing a will). Some changes to the response options and scoring would also be required to ensure that scores were meaningful throughout the range (unlike the range of response on the Coping with Death scale which gives a neutral value to the middle range on a one to seven scale, making it difficult to award meaning to the middle range of total scores). This would potentially provide a single useful measure of nurses' confidence in dealing with aspects of death and dying and may also be useful in assessing benefits of death education courses.

### 6.3.2 - The Findings

There is no previous work with which to compare these important findings on Coping With Death and Death Self-Efficacy and the need for further replication is acknowledged. However, the results from these two scales further emphasise the impression within this study that general nurses may be less well prepared than the other two groups to cope with nursing the dying. The general nursing group reports significantly lower scores on death self-efficacy. These findings are in line with Kelsey (1992) who also reported that nurses felt that they lacked some of the skills and had insufficient training for some aspects of working with the dying. If nurses do not feel adequately prepared to cope with death and dying issues, there are likely to be serious implications for the kind and quality of care being given to patients and families. It is also likely that there will be an impact on nurses, in terms of stress and the effects of doing the work.

Coupled with the findings that many nurses in this sample feel their training was inadequate to prepare them for some aspects of caring for the dying, the Coping with Death/Death Self-Efficacy results raise questions about the nature and quality of training provided for nurses. This may be particularly true of the general nursing group, two thirds of whom reported feeling inadequately trained for some aspects of this work. Palliative care nurses expect to experience many patient deaths and are specially trained to cope with this work, yet 25 percent or more of this sample of palliative nurses still feel inadequately prepared by their training. General nurses also encounter patient death frequently and must be prepared to deal with such an event at any time. Indeed, in many areas of nursing,



other than palliative units, patient death may be of a nature which makes the event even more difficult to cope with (sudden unexpected death, death resulting from violence or the death of a child). Yet it would appear that general nurses may be at a disadvantage in terms of self-efficacy.

## **6.4 - Qualitative Findings**

Although the quantitative approach allows comparison across the three groups of nurses in terms of their perceived competency to deal with death and dying issues, there are aspects of the nursing experience of caring for the dying which are more adequately explored through the qualitative approach. It is important to understand how groups of nurses in different clinical areas may perceive their abilities but there is also a need to try to find reasons why group differences exist and to look more closely at individual responses to patient death. How the nurses cope with the experience, how nurses perceive the experience and what elements of the experience are most important in terms of creating stress are examples of issues which have been investigated through the interviews and diaries in this study.

While coping strategies for dealing with stress are reported in Chapter Four, this chapter focuses on the experience of patient death, in terms of special strategies used to cope with this specific event and other factors which may influence the nurses' ability to cope.

### **6.4.1 - Special Coping Strategies**

In response to question 18 from Appendix IIb, only 40 respondents stated that they had a special way of coping with stress related to the death of their patient. Answers from those who specified their 'special way' included "black humour", "attending the funeral and visiting the family after", "acknowledging the sadness and having a good cry", "reflecting on my working relationship with that patient to consider whether anything else might have been done" and "talking things through with colleagues". The last strategy reflects, once again, the importance of social support and the importance of building and maintaining good relationships among colleagues.

#### 6.4.2 - Ability to Cope

Nurses were asked in interviews whether they thought they were able to cope with death and dying. Most said that they were able to cope but many of the nurses volunteered that they believed they coped at some cost. The costs of coping or effects of working with the dying will be discussed in more detail in Chapter Seven, but costs which were mentioned included “sleepless nights”, “tension at home” and “generally feeling down” (INT 10-GEN). Another very experienced palliative care nurse explained the cost of her work:

*“Yes, I think at the moment I’m going through a time of questioning and finding I’ve lost a lot of my joy out of life..and ..I can’t see the ridiculous side of life at the moment...I don’t know whether it’s temporary or whether...it needs me to be saying, hang on, I ought to get out of here. But if I go out socially I can’t cope with trivia, I can’t cope with party chat. I find it’s taken away...there’s no sort of light side really.....so I suppose that, to me, has been the cost...” (INT3-PALL)*

When nurses were asked what they thought would help them to cope better with the effects of patient death, one response was clearly more important and more prevalent than any other. Nurses would like to have available someone to whom they can talk openly when they need to talk, not at some scheduled time which may be too late or too early or inconvenient for the nurse to fit in among commitments. Among those nurses who were interviewed, this appeared to be a greater problem for the general nursing group. Within hospital settings, there are chaplains available, but the nurses appeared reluctant to approach them and scheduling appointments seemed to be too awkward for nurses with many personal commitments to fit in as well as their work. This may be a factor in the relatively lower perceived coping and self-efficacy ability reported by the general nursing group. However, while there may be greater support available within hospice units, palliative care nurses who work in the community also expressed the need for someone to whom they could talk when they felt the need.

#### 6.4.3 - Coping with Death as a Young Nurse

There appeared to be a consensus of opinion among interviewees that young nurses require considerable support to cope with patient death on the wards and that maturity and

life experience helps one to deal with these events. One nurse expressed the view that 18 years of age was too young to be nursing dying patients and that a person needed more experience of life to do the work properly (INT25-PALL). This attitude had been experienced by another hospice nurse who, in her mid-twenties when she started hospice work, was told by other staff members that they believed she was too young to do the work in a satisfactory manner (INT3-PALL). Another nurse explained that she felt it important to offer young nurses or students the opportunity to be involved in last orders and to talk through the patient's notes in detail, so that the younger nurse would feel confident about the care which had been given (INT6-GEN).

Although many nurses believed that one has to experience a death in order to learn fully how to cope with it, many were also strong in their convictions that death and dying and the related issues could be more effectively dealt with in training curricula. There were suggestions for the use of role playing techniques to help student nurses to prepare for this part of their work. The general view seemed to be that the issues relating to death and dying and caring for the dying and their families should be more fully discussed during training. Some of the nurses who had taken extra courses in care of the dying and/or bereavement counselling felt that they would have benefited from that instruction at a much earlier stage in their careers.

#### 6.4.4 - Stressful Elements of the Nursing Experience of Caring for the Dying

Question b) Which elements of caring for the dying and of patient death create the greatest potential for an appraisal of stress and negative effect on the nurse?

From these data, the nursing experience of caring for the dying appears to fall into three distinct but overlapping areas: what happens prior to death, the event of death, and what happens after the event. Each of these three areas has particular elements which appear to be important in determining what the outcome will be for the nurse, i.e. whether the nurse feels stress during that time and/or whether there will or will not be negative effects of stress related to these events. These elements may vary with the specific role of the nurse.

## 1. What Happens Prior to Death

Table 6.5 - Factors increasing the likelihood of an appraisal of stress in the period before death of a patient

|   |  |
|---|--|
| 1 | Nurse patient relationship - Identification with patient, age of patient, duration and intensity of care |
| 2 | Physical preparation of patient for death  |
| 3 | Nurse/Doctor conflicts about symptom control or care or 'innappropriate' treatment                       |
| 4 | Insufficient time to prepare patient and / or family psychologically                                     |
| 5 | Heavy workloads  |

### Nurse/Patient Relationships

A major factor in the outcome of this experience is the nature of the relationship between nurse and patient. Identifying with the patient (affected by age, personality, similarity of circumstance) tends to increase the level of stress and to heighten the nurse's own fears about illness and death and the effects on families. Many nurses mentioned the age factor saying that it was easier to accept death in the older patients but when the young die, they tend to identify more intensely with the patient and with the trauma for the families. Death of a young patient also tends to raise the feelings of 'the unfairness of life' and, particularly for the younger nurses, raise issues about one's own mortality ( They are my age - could it happen to me?).

The length and intensity of nursing input can have both positive and negative effect. When a nurse cares for a patient for some time, there is increased opportunity to develop a close relationship with the patient, increasing threat of loss during this time. There is also, however, a feeling of satisfaction at being able to help (INT 4-PALL) and of getting to know the patient and their family well enough to understand fully (INT 9-GEN) and to meet their needs. This may increase the nurse's ability to focus on the positive aspect of the work, for example, professional gain (achievable aims) which will affect the appraisal process.

### Physical Preparation for Death

Nurses in this study speak fervently of the importance of preparing their patients and the families for the impending death. They say that when there is inadequate opportunity for this preparation they find the whole experience of caring for the dying patient and the

actual death more stressful. This preparation has several elements. Symptom control is aimed at bringing the patient to the optimum comfort level without blocking his/her mental facilities and is a major commitment, especially in palliative nursing. This can result in a great deal of stress for the nurse when there is conflict of opinion between doctor and nurse about which drug or the amount to be used. This conflict is, in effect, a threat to the commitment to a certain standard of care. Nurses in this sample, especially those trained in palliative care, expressed the view that they feel they have more expertise in making these decisions but sometimes the doctors, who may disagree among themselves, do not respect that expertise.

*"The thing I find most difficult is when we've got a patient . ... who is dying and we need to change drugs from oral to giving them subcutaneously and I can't agree with the GP again on what we might give, that can be very distressing, especially if the patient and the family ends up distressed because in my opinion, .... the symptom control could have been better. I find that very difficult...very difficult. ... because I don't put the drugs up but I advise, I've actually advised some of my nursing colleagues who've been asked to put the drugs up that I wasn't convinced that they were appropriate drugs and that they should be aware of what they were doing and why, because they are ultimately responsible 'cause they've put the needle in and the drugs up. I've had a strong nurse say, I'm not able to put that amount in this syringe and so the GP went off and did it himself which is fine because he prescribes and...he's responsible then. But that distresses me when it doesn't have the desired effect of making the patient comfortable but as alert as can be. It's quite a big issue for me!" (INT 3-PALL)*

### Nurse/Doctor Conflicts

A further area of conflict between nurses and doctors may arise over "inappropriate" treatments which are prescribed for patients who are near death. Although this is said to be a relatively infrequent occurrence, it is a very stressful experience when it does occur. There is a perception among some nurses that doctors are sometimes unable or do not know when to palliate. In some cases, nurses question the medical staff about the wisdom of procedures and may even feel compelled to refuse to obey instructions.

*"No we're talking palliative care, not CPR and all the rest of it ... I remember working at -----the crux was when I was in training and it was a medical ward and because -----was a medical training area, they were putting a central line up and the poor woman, she must have weighed about four stone...they were turning her and had about six goes, different doctors.....and this junior doctor came up and said, right I want a potassium enema done on this lady, and I can remember looking point blank at Sister and saying, I can't do it, I refuse to do that.....and she died the next morning anyway." (INT4-PALL)*

The same nurse recalled another instance where a patient, terminally ill with advanced cancer, had a fractured femur (recognised by the nurse who was previously experienced in orthopaedics). The patient was left overnight before examination by the doctor, was then moved to a general hospital and an operation carried out on the femur before the patient was returned to hospice:

*"...then she came back to us and she was in such a state, I thought this is horrendous...The woman, every time you went near her she just pounded forward at you....and the relatives had such a high opinion of us as well and in fact everything had just about gone wrong that could have possibly gone wrong....This doctor eventually when she did come said, oh give her oral morphine, two point five which is like a couple of paracetamol really and ...consequently she just spat it out and I thought this is going beyond a joke and what she needed was sedating ....a syringe driver up and ..(long sigh)...she died about five o'clock. .... Em well I've got my own views on that....she was in excruciating pain when she came back to us and she was an elderly lady and.....there's all these other view points to it. I mean I think we had this debate about transfusions, the levels of anaemia and so forth....and whether it's worth doing that and I think you have to take each patient individually..... those (side effects of treatment) should be taken into consideration....but that was taken beyond us because she was transferred and so she was under a different doctor...and I mean our doctor actually phoned up and put his viewpoints over but at the end of the day, it's the general surgeon that is going to make the decision. .... Sometimes, yes, ..fair enough have the operation and yes they do get benefits from it and it is worthwhile but then there's always the one that makes you think, well this is just cruel,...and you know...take a step back." (INT4-PALL)*

The above extract highlights several points; a) the doubts held by the nurse about the use of radical intervention in some situations where the patient is in the last stages of life, b) differences in opinion between nurse and doctor about what was suitable pain control, c) there may be differences between doctors about what treatment is suitable, d) the nurse's concerns that the relatives would feel that care had been less than ideal, and e) this is an example of a situation in which the nurse feels that s/he has little control over decisions about patient care. These issues are all related to the nurse's wish to achieve a 'good death' for the patient: the need for a peaceful, painfree death for the patient and a situation where both patient and relatives are well cared for.

On the other hand, some psychiatric nurses, working with the elderly mentally infirm, expressed concern that there is sometimes insufficient effort made to treat physical problems in their patients. The perception seems to be that the age and mental condition of their patients affects the treatment decisions in ways which are not always in the interests of the patient. Because the patient is mentally infirm, there is perceived to be less willingness on the part of some doctors to relieve symptoms (INT14-PSY). One nurse objected to what she interpreted as a lack of respect for elderly patients and an attitude that these elderly patients "have no brain anymore" (INT5-PSY).

### Psychological Preparation for Death

As important as the physical comfort is the psychological and emotional preparation for death for both patient and family.

*"...I consider the sort of counselling and building the relationship as part of the job. So if you got a patient who came in, ... and is unconscious from the beginning, you've not been able to do that part of your job. You can only do the essential nursing duties...you don't get the chance to do anything else. .... I think that maybe you feel that you were cut off before you got the chance to do what was your job." (INT 9-GEN)*

Again, the aim is to facilitate a 'good death' wherein the patient accepts their impending death, completes their family farewells and reaches their final hours in a peaceful state. In

addition, nurses see their role as helping the relatives to cope with events as they happen and to produce "a positive result" for the relatives as well as the patient.

*"You've learned how to manage a situation - I mean you hope you're not manipulating a situation but you do hope to manage it and you do hope to get a positive outcome out of it.....You would hope to achieve a death that the relative will get over....that the relative won't have nightmares over or won't feel guilt.....so that somebody can grieve positively and that it doesn't actually hinder the rest of their lives, then that's what we're trying to achieve and I don't know if we ever know if we do." (INT 25-PALL)*

This preparatory work is a more stressful experience for the nurse when the patient is in denial or is unaware of the prognosis. The nurse may be unsure of what to say to the patient and how to deal with relatives who appear to expect miracles. One nurse expressed her embarrassment at feeling it necessary to lie to a patient, an act which she viewed as a betrayal of trust (INT 23-GEN). During this time, nurses are often required to be part of very emotional family scenes which may involve family conflicts or farewells or in the absence of family, may be the only person with whom the patient shares their final thoughts and wishes. Although some nurses say it is a privilege to share at this level of emotional involvement, they say it can also be very stressful. Some nurses say that they have felt resentment at having to extend their role to being a substitute for a family member when a patient is dying without relatives present. In theoretical terms, these events may stretch the nurses' resources to the point where they feel their professional and/or personal well-being is threatened. This may also indicate that the nurse has set boundaries between professional and personal demands and felt pressured into overstepping that divide.

The opportunity to prepare the patient physically and mentally before death, and to help relatives to prepare, appears to be a significant part of the nurse's own preparation for the impending event. This opportunity is lost in sudden or unexpected deaths ("*...it is a situation that you can't manage...*" INT1-GEN) and where patients arrive at hospital in the very latest stages of terminal illness. One nurse explained why those scenarios are so stressful:



*"(dealing with the patient who comes into hospital only 48 hours before death) goes against everything you have learned and against every personal philosophy which is to care and to give your very best - prepare the patient, help the patient, ease the pain, ease the mental pain...give them the satisfaction of seeing their relatives not sitting there with tears rolling down their faces or anguished faces, a sense of calm, peace...that all goes..... You haven't prepared for anything yourself, personally...everything you do is two days late or a week late or they've got terrible bowel problems...and that is agony and you can't do anything now, you can see that death is imminent.....but you know they're in physical pain....you hope that the doctors can prescribe strong analgesia but that is not satisfactory...because all you do is take away any moments of lucidity." Would I be right in saying that it doesn't give you the opportunity to 'manage' the death? "Yes, for them or for yourself...you haven't had time to put it all into perspective in your own head let alone help them, prepare them or the relatives." (INT 19-GEN/PALL)*

### Workloads

For some nurses, especially those in palliative care, a major cause of stress in this part of the process is related to working with many terminally ill patients at one time. There is the need to care for each and every patient in the sure knowledge that all of their patients are going to die within a very short time. This can produce a sense of overload for the nurse.

*"....I've had a bad day today and it's been...things you've picked up along the way and...you know one grief on top of another grief, one sadness on top of another sadness and you know, how many more can you pile into a day, and...what am I going to do with them when I get home?"(INT 3-PALL)*

The environment in which the nurse is caring for the dying can have a strong impact on the stress felt by the nurse. Working in patients' homes sometimes results in a closer, more informal relationship between nurse, patient and family. This can make the experience more emotional, without providing the formality of the hospital environment which can be useful to help the nurse to stay in control, not only of their own emotions, but of the demands put upon them by the family. A Marie Curie nurse explained that when one leaves a ward, there is an opportunity to hand responsibility to someone else and that

makes it easier to *"leave worries and stresses behind"*, whereas, when nursing in the home, *"you are on your own with the concerns for the relatives...and it's hard to let go. You feel a greater responsibility for the families"* (INT 21-PALL).

## 2. The Event of Death

There is, among these nurses, a very realistic attitude and acceptance that dealing with death is a part of the natural process of life. Many nurses said something similar to :

*"...It's what we're all born to do at the end of the day."* (INT1-GEN)

These data do however, highlight several factors, pertaining to the nature of a patient's death, which may play a role in the generation of an appraisal of stress.

Table 6.6 - Factors pertaining to the nature of a patient's death which may increase the likelihood of an appraisal of stress

|   |   |
|---|---|
| 1 | Level of success in achieving goals for patient and family prior to death (the good death ideals) |
| 2 | Failure to achieve the goals for patient and family at time of death                              |
| 3 | Sudden or unexpected death  |

## Achieving the 'Good Death'

As shown by the findings presented above, the amount of stress generated by the event itself is affected by the level of success in achieving the goals during the time preceding the death, because that success or failure will largely determine the nature of the death. Nurses find painful death unacceptable in this era and also seem to believe that they should be able to alleviate most of the mental distress for the patient (INT 19-GEN/PALL). The following quotation from a Marie Curie nurse demonstrates the feelings of hopelessness and uselessness experienced by a nurse who was unable either to ease the dying patient's distress or the relative's distress.

*"I'd been going to this lady for quite a few weeks and it was the way she was dying - she was sort of choking and I felt so helpless and her son was so upset... I had got to know him a bit and I felt so sorry for him...and I just felt so sorry for her. I felt she was having*

*an awful death.....I felt so useless.....You wish you could do something and.... (INT 21-PALL).*

Therefore if they achieve "a good death", explained as a death which is painfree, peaceful, with relatives present and prepared, nurses say that their job has been well done and that this is an "*acceptable death*" (INT 19). When a patient struggles for life to the very end, perhaps being "very verbal", when the death results in unpleasant effects such as bleeding, or when relatives are very vocal or expressive in their distress, nurses say that the level of stress is increased.

### Sudden Death

Sudden, unexpected deaths appear to be very stressful for most nurses, and in some areas of psychiatric nursing, where death is infrequent and usually violent (as in suicide), it carries particular implications for the nurse. In those cases, the first consideration may relate to apportioning blame. The feelings of several nurses working in acute psychiatric wards were summed up in the following extract.

*"I think death in Psychiatry is always unfortunately flavoured with - well, whose fault was it? A lot of nurses in psychiatry see death as a failure and disciplinary action because something must have gone wrong for the patient to have killed herself or himself. Somebody must have failed in part of their duty...didn't spot something...didn't react in the right way...judging with hindsight is a powerful management tool used against nurses." (INT 22-PSY)*

### A Sense of Relief

Several nurses confirmed that they sometimes share in the relief felt at some deaths when the patient has suffered (INT 19-GEN/PALL), when the prognosis is very poor (INT 7-GEN) and/or when the quality of life for the patient has been very poor (eg long-term dementia sufferers) (INT14-PSY).

### 3. The Events After Death

#### Effect of Previous Events

How a nurse feels after the event of patient death will be affected by the two previous stages. Almost all of the nurses emphasised that every death leaves staff feeling sad and bereaved to some extent. The kind and intensity of the nurse/patient relationship which had developed determines to a great extent the depth of feeling associated with each bereavement. One nurse said it resembled *"the loss felt when you lose a member of your extended family"* (INT 16-PSY). If the care and preparation stage has not been successful in the nurse's terms and/or the death has been particularly harrowing or unpleasant, the nurse may find the period after patient death a difficult and stressful time. There are, in addition, several elements in this stage which deserve some attention, for they appear to have a serious influence on the long-term effects on the nurse of working with the dying.

Table 6.7 - Factors in the period following patient death which increase the likelihood of an appraisal of stress.

|   |                                 |
|---|---------------------------------|
| 1 | Care of the body                |
| 2 | Care of the family              |
| 3 | Lack of opportunity for closure |
| 4 | Numerous deaths                 |
| 5 | Missing the death               |
| 6 | Rate of patient turnover        |

#### Care of the Body

The first of these is the procedure of caring for the body, whether it involves the full last offices or only delivering the body to some other department where final care is given. Nurses often say that they prefer to do the final care and view it as an important part of the whole process.

*"If you've been able to contribute towards a peaceful death...that is your rewarding bit at the end of what you've been able to do for them. What you do at the end is the winding down and coming away from it"* (INT 9-GEN)

### Care of the Family

In many ways, the care of families of the dying is as important to the nurse as the care of the actual patient. Therefore, a considerable part of the work after the patient death centres around the relatives. This part of the nursing role is considered highly stressful, as seen in the quantitative data on sources of stress (Chapter Four). Some nurses expressed their feelings of helplessness when faced with grieving relatives (INT23-GEN). The caring and counselling work may be prolonged if the family are very distressed and relatives may continue to visit the ward to talk to staff about their deceased loved ones. One psychiatric unit, where patients are elderly and mainly sufferers of the dementias, organises periodic tea-parties for relatives of those who have died as well as those who are still visiting the patients in the unit.

### Closure

Attending the funeral of the deceased patient is, for some nurses, a way of finding closure (INT9-GEN). It is also, however, often done at the request of the patient or the bereaved family and can be an emotional and stressful event in itself. If there are several funerals to attend within a short time, there can be an accumulative effect which puts a strain on the emotional resources of the nurse.

### Numerous Deaths

If the death has been one of several, there is a greater likelihood that there will be some negative effect. From the practical perspective, it may become difficult to maintain a positive atmosphere in the nursing unit (INT 7-GEN). Both patients and staff may be affected and the altered atmosphere can have a negative effect on how other patients and relatives cope with their own situations. This, in turn, makes the nurses' task of caring for those patients and relatives more difficult and stressful. A view expressed by several nurses was that a number of deaths in quick succession can make it difficult to "*keep things in perspective*".

### Missing the Death

When a nurse has had considerable input into the care of a patient and then is not present at the actual death, there can be repercussions. The sense of loss may be heightened, especially if the relationship was strong, and nurses say that they experience a range of feelings from " *guilt, anger and letting the patient down*" (INT 21-PALL) to " *feeling suspended, .....no closure*" (INT 9-GEN), and many referred to a sense of " *unfinished business*". For nurses who experience many patient deaths, there are some occasions when missing the death brings a sense of relief at not having to cope with yet another death. This relief may be coupled with guilt about feeling that relief (INT 25-PALL).

### A Sense of Relief

A sense of relief may also be present if the nurse has not been able to achieve the peaceful and pain-free kind of death which seems so desired. The death may be seen as ending the need for further struggle with this challenge.

*"Sometimes I feel that I'm getting too used to death and the relief I feel is because I could not give this patient what I wanted, not that I couldn't give her what she wanted."* (D 6-PALL)

### Rate of Patient Turnover

The rate of patient turnover in hospitals was reported by some nurses as a source of stress and this became a serious matter for those whose patients had died. During the period following death, nurses say they find it very difficult when the bed where someone has died is filled with a new patient within the same day. Hospice nurses say that with the emphasis on community care which keeps patients at home until they are very near death, the whole situation becomes more like a production line because patients are admitted and discharged so quickly.

*"This last 18 months has become more stressful..much more stressful..than in the previous years because the patients we are having in now are terminally ill...and much further on in their illness. When I first worked at the hospice..we used to have patients that came in*

*for respite care... now... because the community are beginning to look after them in their own homes more...we are getting patients much nearer the end of their lives and I find that very stressful...we have them in for 24 - 48 hours and they die and you've got to pick up all the family stress and everything that follows on...dealing with people you haven't really had time to get to know.....sometimes I begin to feel it's more like a production line....because we're getting these people so late, they are coming to us as strangers as do the family and you have to try and deal with it the best way you know how. Following a death we used to leave the beds open for 24 hours, they would be empty. Now some of these beds are filled within the same day as the death and I find that very distressing..very distressing!" (INT 24-PALL)*

#### 4. Factors Affecting the Whole Experience

##### Previous Experience of the Nurse

There are also some factors which impact on the whole experience for the nurse. The age of the nurse and the amount of experience (of life as well as in the profession) are important. Generally, nurses found their first experience of patient death very distressing and said that experience of life and of patient death helped to get things into perspective. Further, having coped with a patient death, future ones became somewhat easier. One nurse said *"You never get used to death, you learn to cope with it."* (INT 9-GEN)

##### Professional Self-Image

The beliefs held by the nurse about professional self-image may impact significantly on the appraisal process. For nurses who believe that they should not show their emotions when in the presence of patients, there may be a greater perceived threat or challenge in the face of such emotional work. There was evidence in this study of both views. One nurse expressed feelings of guilt because she had cried in front of a family who were already distressed. Other nurses commented on the need to be strong and in control.

*"You have to get through.. you can't go to pieces when you've lost probably one or two because the third family is just as important as the first one and they deserve the same care. It's not wrong to cry or show emotion but families need support and they need to*

*feel safe in your hands. They need someone steady, reliable...if you're down it doesn't help them so you set aside your own feelings and reactions until a later time."* (INT 11-GEN/PALL)

and

*"... I feel I have to fight the tears back. There's times when I wish I could cry with the family....but you can't...you're there for them. If I cry I'm letting them down and letting myself down so what I usually do is when I've left I have a good cry in the car..... and maybe talk to somebody....I may call one of the ladies."* (INT 21- PALL)

Other nurses said that they felt it was acceptable, possibly even valuable, that families saw nurses' emotions. One nurse had apologised to a bereaved family for crying when their loved one died (INT 21-PALL). The family, however, explained that they felt comforted and were grateful that the nurse 'cared' for their loved one.

### Personal Philosophy

One thing which nurses say helps to reduce the stress associated with patient death is the development of a philosophy of acceptance of death, especially in the elderly and, more specifically, acceptance of the "acceptable" or "good" death (INT 25-PALL).

## **6.5. - Discussion (Qualitative Data)**

### **6.5.1 - Coping With Patient Death**

Only 40 of the respondents acknowledged that they used a special strategy to cope with stress associated with patient death even though, as reported previously, there appeared to be a perception that this stress differed from other work-related stress. When interviewed, most nurses agreed that they coped but volunteered that there was a cost to their coping. These findings add to the perception gained from the quantitative data, that nurses have a perception that they could (or should) cope better with this work.



Nurses also appear to have definite ideas about what would help them to cope more easily. Better access to one-on-one social support was highlighted as the main request by these nurses but they also emphasised the importance of support for younger nurses who encounter patient death, more open discussion of death-related issues and earlier and more education/training in specific aspects of caring for the dying.

#### 6.5.2 - Stressful Elements of the Nursing Experience of Caring for the Dying

This investigation was undertaken with an exploratory approach, to gain a detailed account of nurses' perceptions of the particular elements of patient death which give rise to an appraisal of stress. The model of the stress process as described by Lazarus and Folkman (1984) provides a useful framework to understand why, in theory, each of the above elements is an important determinant of the kind of appraisal a nurse is likely to make of the situation, i.e. whether it is/is not a stressful situation. Using that framework, each of those elements plays a part in determining whether or not a situation taxes or exceeds the nurse's resources and/or threatens his/her well-being, professional and/or personal. If there is to be any attempt to alleviate the stress associated with patient death, it is important to recognise the elements in that process so that, wherever possible, corrective measures may be directed towards the specific element.

Since this is a report of nurses' perceptions, they may or may not accord completely with reality in the workplace. However, the validity of the perceptions of this sample of nurses is strengthened by their similarity to other findings such as those of Field (1989) - the impact of long intense periods of nursing a patient; Fisher (1991) - the importance of identification with patients and the tendency to question care which was given prior to death; Hunt (1992) and McNamara et al. (1995) - the nurses' desire to produce the good death which included symptom control and a pain-free, peaceful death; and Katz (1996) - the challenges of providing the kind of care the nurse perceives to be essential or correct. The emphasis in this study was on those perceptions which caused the nurses to decide that a particular experience of patient death was stressful. If the Lazarus and Folkman framework is accepted, the perceptions are critical in the development of an appraisal of stress. Therefore, remedial measures may need to be focused on changing nurses' perceptions as much as on the realities of ward situations.

Several of the environmental elements such as working environment, problems with symptom control, patient turnover, bed use and disagreements with doctors may tax or exceed the nurse's resources in a very practical way as well as in a psychological way. Changes of a practical nature (such as reduced caseloads or changes in working practice and environment) could undoubtedly improve the situation for the nurse. Greater consultation and agreement between members of medical teams on treatment of patients might help to reduce staff tensions and reassure the nurse that standards of care were being met. The result might be a change in nurses' perceptions and a reduction in the threat to both professional commitments and emotional resources. Theory would suggest that this would result in a reduction in the amount of psychological stress incurred.

Other elements place a severe strain on the emotional resources of the nurse. Identification with patients (and other aspects of the nurse/patient relationship), the nature of nursing input, physical and psychological preparation of the patient, preparatory and counselling work with the family, may be more difficult to change to accommodate needs of both nurse and patient. However, the quantitative data provides clear evidence of a perceived lack of preparedness to deal with some aspects of caring for dying patients and their families. The importance of these perceptions is underlined by the Lazarus and Folkman (1984) framework which suggests that the threat or challenge within a situation will be reduced by the perception that one will be able to cope with the imminent event. This emphasises the need for nurses to have confidence in their ability to meet the challenges in dealing with dying patients and their families.

One major difference in commitment between the three nursing groups is that palliative care nurses are focused on the best care possible for patient and family before and after death, rather than the commitment to curative care held by other nurses. Potentially, this leaves those other nurses (for example on a general ward) more vulnerable to the threat of failing to meet professional commitments when a patient dies. Thus, a patient's death may be perceived as a failure by some nurses in a general care ward. However, for palliative care nurses, a sense of failure may not be related to the death itself, but rather to the failure to provide that 'best care' which often equates with or, at least includes, achieving a 'good death'.

There is some evidence in the data that general nurses do have these feelings of failure when a patient dies. They make comments like *"with the best will in the world there was nothing we could do"* (INT 1-GEN), *"in spite of all our efforts, that child died"* (INT 18-GEN). They refer to patient death as 'losing a patient'. Palliative care nurses start from a different perspective, knowing that the patient is terminally ill. *"I'm working in that environment ...that's (patient death) what I expect."* (INT 4-PALL), and *"I can do nothing about the fact that the patient is dying, so..I don't question that anymore. As long as I can achieve that desired and comfortable death, I can accept it"* (INT 25-PALL). As a result, the main possibility for failure is related to the kind of care and the kind of death produced for the patient.

However, there is also evidence in the data that most general nurses have an understanding of holistic care and a desire to provide it in all areas of their work. As a result, once they know that a patient is going to die, they adopt broadly the same commitments to care for that patient as those held by palliative care nurses. That is, they want the patient to have a dignified, pain-free, comfortable death with relatives present and they want time to prepare patients and families before death and to care for families after. It is in the face of this new commitment that there appears a new threat to nurses, especially nurses who are not working in hospices or palliative care units. This is the threat to the commitment to, and ability to achieve, this good death.

In palliative care units, the focus is on delivery of this kind of care, nurses are specifically trained in this kind of work, and the whole ethos and culture of palliative units or hospices is focused on meeting that commitment. Palliative care nurses in this sample appear to have an expectation that this good death can be provided most of the time. When they fail to do so, causes of the failure may be family absence or conflict which has distressed the patient, the patient having arrived at hospice too late to allow proper preparation for a comfortable death, or problems related to symptom-control (which may or may not be related to disagreements with doctors). Occasionally, caseload and staffing levels may play a role (INT 4-PALL). Failure to provide the good death causes stress for nurses. When the failure is perceived by the nurse to be the result of some failure to meet patient's physical or psychological needs, the stress is caused, not so much by the actual death, but by their perceived failure to meet certain standards. (INT 4-PALL, INT 19-GEN/PALL).

The other nurses in this study, especially the general nurses, seem to have less confidence in their ability to meet this commitment. Reasons for this lack of confidence appear to be threefold. They include doctors' attitudes towards treatment and palliation, general culture or ethos on the wards and nurses' own lack of training to cope with death and dying issues.

There is a perception held by some nurses in this sample that doctors too often do not accept death as a natural part of life and that they put too much emphasis on life at all costs (INT 4-PALL). One nurse interpreted the doctor's offer of chemotherapy to a patient who was very near death as the doctor's need to cling to life, although the nurse acknowledged that some, if not most, patients would expect every last chance to be offered (INT 11-GEN/PALL). The nurse felt that because doctors behave in certain ways, patients feel obliged to 'try anything'. It is this kind of attitude which results in what nurses see as 'inappropriate treatments' for patients who are near death. These attitudes, coupled with nurses' perception of a lack of understanding (by doctors) of palliation, seem to create a situation which makes nurses in general care units doubt their ability to produce the kind of care and the good death to which they are committed. It is this doubt which increases the burden of stress felt by nurses who care for dying patients.

General nurses deal with many of the same problems as palliative care nurses. They have, however, an additional problem related to the general nursing ethos or culture within their area of work. The feelings of several nurses were echoed in the following extract from an experienced nurse who was moving into palliative care the following month:

*"There is a tendency in the general wards to shove dying patients into side rooms...they're not forgotten about...but...given care...but not in the right way...the most important things like sitting down and talking. I mean even if they got the pain and symptom control right ... which they often didn't, they omitted to sit down and talk...they sort of write them off before they have gone." (INT 11-GEN/PALL)*

In contrast to dying patients in a hospice who receive the full focus of attention of all the medical personnel, it is perceived by some nurses that, on a general unit, when the patient has been diagnosed as terminally ill, in some respects the patient loses the focus and attention of medical personnel. Instead of a new focus of providing best possible care

aimed at the good death, sometimes the patient is 'written off'. Many nurses believe this is wrong.

There are several instances in the interview data which underline nurses' feelings that while holistic care is desirable and possibly even expected by the patient, it is too often not given for reasons of lack of time or staff. In the case of the dying patient, the absence of good holistic care may be because the 'system' or 'practice' within the unit makes it difficult to provide such care. It may also be due, in part, to a lack of ability on the part of the nurse (Fallowfield 1991). To reiterate, evidence from both qualitative and quantitative data in this study suggests that nurses perceive themselves and/or their colleagues to be less than adequately prepared to cope with some aspects of this work. Some nurses are said to be "*embarrassed by death*" (D 3-GEN), are unable to talk openly about death, and behave as though nothing extraordinary has happened (INT 5-PSY).

In psychiatric nursing, patient death is generally of one of two kinds. The death either follows long periods of mental infirmity where patients are usually elderly or it follows a violent act such as suicide. In the case of the elderly, pain control and psychological care of the patient are less likely to be major issues. However, as has already been stated, there are issues of treatment and care which do cause nurses some concern. Violent deaths, by their nature, cause a different set of problems for the nurse. Psychiatric nurses in this sample report that it is the aftermath and investigation which causes the stress for the nurse who may fear sanction for some aspect of their work. The qualitative accounts suggest that these situations cannot be studied within the same framework as patient death in the other two clinical areas in this study.

## **6.6 - Summary**

While the need for further work on the new scales used in this study is acknowledged, data on Coping with Death and Death Self-Efficacy reveal good reliability statistics for both scales. The important new findings from these two measures suggest that nurses, especially those in the general nursing group, perceive themselves to be somewhat inadequately prepared to cope with death and dying issues. They rate their abilities lower than the palliative group, yet general nurses are expected to cope with frequent patient death.

In interviews, nurses generally expressed the view that they coped with their work with dying patients but at some cost to their own quality of life and only 40 respondents acknowledged that they had special ways of coping with stress related to patient death.

In the more exploratory section of this part of the study, the aim was to access, through qualitative approaches, detailed information about what nurses perceived to be the specific aspects of the experience of patient death which led to an appraisal of stress. The results are validated by their similarities to previous findings. The data are also important because of the manner in which they appear to show how, within one overall experience, there are three separate but related groups of stressors.

The elements of the experience which were perceived by these nurses as causing them to appraise a patient death as a stressful event were largely divided into three categories. 'Events prior to the death' included the level of identification with the patient, duration of the period of nursing care, ability to prepare patient and family for the impending death. the factors related to 'the event of death' itself included the level of success at achieving good death ideals, the nature of the death (sudden or unexpected), and distress either of the patient or the relatives. 'Events after death' which affected the amount of stress experienced included the lack of opportunity for closure, having missed the death of a patient and caring for the relatives. The previous experience of the nurse, his/her professional self-image and personal philosophy were also said to impact on the amount of stress associated with patient death.

An understanding of these separate groups of stressors within the experience of patient death may provide another perspective from which to approach changes to nursing practise which might alleviate nurses' stress in this area of work.

This chapter has focused on nurses' perceptions of their experiences of patient death and their ability to cope with that experience. It was noted that nurses did acknowledge that they cope, but often at a cost, and that their work with dying patients does have an effect on their lives. The next chapter will focus on the costs and effects of the work which have been reported by the nurses in this sample, and will address the issue of accumulated loss.

## **CHAPTER SEVEN**

### **Results and Discussion: Effects of Working with the Dying**

#### **7.1 - Introduction**

##### **7.1.1- Research Questions**

- a) What are some of the effects on the nurse of caring for the dying?
- b) Is there evidence of the phenomenon which has been called 'accumulated loss phenomenon' (Adams et al., 1991) or is burnout (Maslach and Jackson, 1981) a sufficient concept to explain the symptoms reported by Adams et al.?

##### **7.1.2 - Procedure**

Question 15 on the purpose-designed questionnaire (Appendix IIb) asked nurses to choose, from a list, the three most important main effects they felt after patient death. They were given the option of 'nothing at all' as well as an opportunity to list other effects which had not been included in the list.

The issue of accumulated loss has had very little previous attention and, in this study, was approached in a very exploratory manner. The questionnaire used by Adams et al. (1991) was used to gather information about the Accumulated Loss Phenomenon to assess whether there was evidence of the existence of the phenomenon. Those data were compared with the data from the Maslach Burnout Instrument. Other sources of information were the interviews and diaries.

##### **7.1.3 - Data Analysis and Comment on the Use of Factor Analysis**

Frequency information was computed for the responses to Question 15 (see Appendix IIb) relating to main effects of patient death.

Chi-Square tests were run on all items in the Accumulated Loss Phenomenon scale to assess whether nurses' group membership was associated with response on individual questions.

In the original paper on accumulated loss, Adams et al. (1991) report that they used data from 100 respondents and 92 questions (one question is missing from the published account which was used in this study). They state that analysis of this data, using a 5-factor varimax rotation, revealed five characteristics of accumulated loss phenomenon. However, Child (1990) and Polit (1996) both state that a larger sample is required to complete a reliable factor analysis on 92 variables. No other information has been forthcoming from the authors, regarding other aspects of the factor analysis of data in the original study.

Normally, to compare results of two factor analyses, one would attempt to replicate samples, variables, and coding and analysis methods (Polit, 1996). In this case, it is impossible to do so. However, in the attempt to find some evidence of the existence of the phenomenon described by Adams et al., the Accumulated Loss Phenomenon (Adams et al., 1991) data from this study were subjected to exploratory factor analyses. A 5-Factor Varimax rotation analysis, using the default (principal components) method of extraction and a maximum of 25 iterations, was carried out on all 91 items to check results against those in the original paper (Adams et al., 1991). In view of sample size ( $n=300$ , considered small when using 91 variables in factor analysis) and a lack of normality in distribution, this may be seen as an inappropriate use of factor analysis. The method was used only as a method of assessing the previously published findings.

A study of the ALP questionnaire suggested that some of the items may not correlate with others. Since factor analysis is about finding factors which explain relationships among many variables, the variables must be related if it is to be appropriate to use factor analysis. Using all of the variables, the correlation matrix revealed that many of the items showed very little relationship to other variables. In a very large correlation matrix, some variables may show relationships purely by chance and a correlation coefficient lower than 0.3 implies a relatively weak relationship. According to Polit (1996, p 349), "If the correlation matrix consists mainly of correlation coefficients with an absolute value less than .30, there is probably nothing to factor analyze (sic)".



Therefore, it was decided to eliminate those items which, in the correlation matrix, had fewer than three correlation coefficients equal to or greater than 0.3. This resulted in 35 items which were used to run the factor analyses. This also meant that, using the whole sample, sample size was adequate for the analysis. Although sample size for the subgroups (approximately 100 in each group) within the overall sample would not normally be considered adequate for factor analysis on 35 items, it was decided to explore the data in this way for purposes of comparison. The data from the whole sample were used and then data from each nursing group were analysed separately and all results compared. Varimax rotations to extract five factors (Adams et al., 1991) and to extract factors having eigenvalues greater than one were used (eigenvalues are the sum of squared loadings for each factor and describe the amount of variance in the factor solution which is explained by that factor). Factors which have eigenvalues of less than one are unimportant because they represent less variance than could be attributed to one original variable (Polit, 1996). These results were compared to determine the presence of underlying factors which might support the concept of accumulated loss phenomenon.

Factor analyses using Direct Oblimin rotation (the oblique rotation method offered by the SPSS software package), extracting factors having eigenvalues greater than one, and analyses limited to five factors were also carried out using the 35 items. While it would be expected that some factors might be correlated, therefore making the oblique rotation the more desirable method to use, there was virtually no difference between the methods in the pattern of item clustering (see findings reported below).

There are many criticisms of factor analysis and it is a technique which is frequently misused (Kline, 1994). Researchers often disagree about the methods used and interpretation of results of factor analysis. Further, it is difficult to replicate factor analysis but Kline (1994) states that sound methodology can overcome this difficulty. In this attempt to explore the existence of the concept of accumulated loss, it is acknowledged that the use of this technique may not be entirely appropriate but it is argued that, being mindful of the shortcomings within the sample and the data, it is a necessary and useful part of the process of responding to the original publication.

One of the questions being addressed in this study is whether a unique phenomenon of accumulated loss actually exists or whether the characteristics reported by Adams et al. (1991) are symptoms of burnout. This required a comparison of results of the accumulated loss questionnaire with the results of the Maslach Burnout Instrument. Burnout is a three-dimensional concept according to Maslach & Jackson (1981) and each of the three elements of the burnout syndrome were addressed separately. Definitions of the three elements are given by Maslach (1993, p 21-22 - see above, 1.4.3). Those items on the ALP scale which appear to relate to, or be symptomatic of, the three elements of burnout as they are defined, were grouped, and their total scores computed. Some of the items in the ALP scale might be seen to relate to more than one of the elements of the MBI scale. Spearman's rho correlation tests were carried out on scores for the burnout elements and those from the ALP item groups. Appendix XI shows the items from the MBI for each sub-scale and the items from the ALP questionnaire which were considered to be related to each of the three sub-scales for this investigation.

## **7.2 - Findings**

### **7.2.1.i - Effects of Working With the Dying - Quantitative Data**

Question 15 (Appendix IIb) asked nurses to choose up to three main effects felt after the death of a patient. The list included 'nothing at all' as a possible effect and they were also given the option to report other effects which were not given. The data showed that, of the sample of nurses, 88 percent report sadness as one of the main effects they felt after patient death and 82 percent gave relief for the patient as a main effect. Ten percent of those responding said they felt anxiety and nine percent felt guilt after a patient death. Only 56 nurses, or 18 percent, gave more than two main effects.

### **7.2.1.ii - Effects of Working with the Dying - Qualitative Data**

The qualitative data provided much more insight into the broader range of effects which working with the dying has on nurses.

### Personal Attitudes

Because patient death touches the nurse at a personal level, it also has a tendency to bring back memories of personal experiences in a way which other work stress does not (INT 16-PSY). Nurses in this sample frequently reported reflection on some aspect of one's own life and mortality to be a result of doing this work. Several interviewees said they had developed a 'live for today' attitude to life. Nurses explained their fears about how they would be cared for when they were elderly (INT 5-PSY, INT 3-PALL), concerns about the issues of unnecessary treatments (INT 6-GEN), and fear of experiencing the loss of choice (especially about whether they are cared for in hospital or at home) (INT 3-PALL), all related to situations which they see among their patients.

The following two extracts demonstrate concerns, expressed by some nurses, that they had lost their sense of humour, they were unable to cope with people who complain about trivia, and their own emotions had become blunted.

*" When I have had to deal with a dying person I feel like shouting at someone if they are being difficult about a trivial thing ....I want to tell them what I've just had to do, but of course I smile sweetly.... " (D 4-GEN)*

*"I sometimes think my emotions are getting blunted...this patient's death I think I might already have forgotten if I hadn't had to write it down but if I didn't put it to the back of my mind it would overwhelm me." (D 6-PALL)*

Nurses who see many patients die say they sometimes get life out of perspective and must remind themselves that not everyone has cancer or not everyone is sick. Those working in elderly care said that they sometimes forget that many elderly people are fit and well (INT 7-GEN).

### Professional Attitudes

Both personal and professional attitudes may be affected. The effect of some treatments on quality of life for patients leads some nurses to question their use even though those treatments may prolong life for a considerable period of time (INT 6-GEN).

### Fear of Death

Some nurses said that when they experience frequent death, especially if they have identified with a patient's circumstances, their own fear of death is heightened (D1-GEN) and they think about death and dying more often (INT 25-PALL). However, other nurses said that working with the dying makes them more 'mature' in their approach to personal fears of loss and their own death. They said they cope with, rather than manage, their fears (INT 1-GEN) because of their experience.

### Effect of Multiple Deaths

Multiple deaths "*can be quite devastating*" (INT 6-GEN). It "*takes a while to get over a death and the second one makes you feel that little bit worse*" (INT 7-GEN). "*Each death brings it all back*" (INT 18-GEN). One nurse spoke of "*going into auto-pilot*" (INT 11-GEN/PALL) when she wasn't over one death but had to cope with another. Another nurse related how she was unable to support her colleagues when they were upset because "*you have too much of your own stuff (to cope with)*" (INT 3-PALL). One of the diarists, after writing about the death of a young patient, the sense of sadness and bereavement which followed, the relief, and questioning her reasons for staying in palliative work, wrote:

*"I am afraid for my future health with the caseload I have and will have but cannot find a way out of the alley of palliative care into which I have travelled."* (D 10-PALL)

### Effect on Well-being

Nurses are aware of the effects of their work on their own physical and mental well-being. Three nurses admitted to having taken time off because they could not face another day of patient death. Several others spoke of feeling drained and burned out and of having nightmares and sleepless nights after particularly difficult deaths.

### Personal Lives

Many of the nurses talked about the stress of doing the work and how it had affected their personal lives. (See also 6.4.2) Some had marital difficulties which they believed stemmed from their being constantly under stress at work and having insufficient emotional resources left to give to the family when they returned home. Other nurses said that because their work upset their families or partners, they could not share or confide in those who would normally provide social support.

*"It's very difficult to share my work with my family.....my husband finds it extremely (distressing)...I can't share with him, it upsets him.....I can see the tears welling and he has to walk out of the room." (INT 3-PALL)*

### Effect on Others' Perceptions of the Nurse

Caring for the dying affects others' perceptions of the nurse too. When a nurse suffers a personal bereavement, it is not uncommon for other family members to expect support from the nurse and to expect the nurse not to need support for him/herself.

*"Last year when 3 relatives died and I had to support my own family I was almost at the point of resigning as I had no bolt-hole left and felt unable to take any more" (D 1-GEN)* and as another nurse explained,

*"Well, I thought I'd be able to cope wonderfully when my nan and grandparents died but that's totally to the contrary.....the rest of the family, particularly my mother thought I'd be able to cope wonderfully as well and I found that quite stressful 'cause I'm thinking...hang on a moment, this is personal you know! It's something different...and I felt a lot was put onto me... by immediate family..... If I was to cry, that was showing a weakness and my mom couldn't cope with that. You know, ..oh come on, pull yourself together, you work with it everyday, .....in that situation I felt I was a listening post but nobody was listening to me..." (INT 4-PALL)*

### Range of Emotions Experienced

The value of open-ended qualitative questions, such as those used in the diaries in this study, is underlined again in the data which suggest that there is a vast array of emotions experienced by nurses involved with this work. They range from anger and frustration to guilt and fear. One nurse wrote:

*"I think what I usually feel is a myriad of feelings like a bereavement - because I am bereaved to a greater or lesser extent every time a death occurs. Angry, confused, sad - the only feelings I don't experience are shock, disbelief and denial!" (D 10-PALL)*

It is also evident, however, that patient death can be a positive experience in some ways and caring for the dying can contribute substantially to job satisfaction, as the following four examples show.

*"She had died very peacefully and had wanted to die. This 'type' of death can reduce my stress levels because I feel satisfaction that the team have worked together well with the patient to achieve a peaceful, symptom-free death." (D 11-PALL)*

*"Once fear of death has been overcome, and one can be of comfort to both patients and relatives, it is a privilege to be involved." (D 3-GEN)*

*"I would say the frustrations on the whole outweigh the satisfactions, but when the satisfactions come, ...they're so big that you just forget...It makes everything else worthwhile". (INT 4-PALL)*

*"...there's so much job satisfaction in this job and when it goes well, it's good but also it's hard and it's sad, so it's...that fine line between surviving and sinking". (INT 3-PALL)*

These qualitative data, combined with the quantitative data reported in 4.2.2.i, that palliative care nurses report less stress associated with the lack of opportunity for personal growth and advancement, suggest that many palliative care nurses find their work immensely rewarding.

In summary, and in response to the research question (a), nurses report a wide range of effects which they attribute to their work with dying patients. The value of the qualitative portion of this study is again highlighted by the richness of the data. As well as the very wide consensus that sadness is the main emotion felt following a death, nurses report a wide range of other emotions, a tendency to reflect on their work, on past experiences and on their own fears. Personal attitudes, relationships and well-being can also be adversely affected. However, the experience of patient death and caring for the dying can have positive rewards for the nurse.

### 7.2.2 - Accumulated Loss Phenomenon - Quantitative Data

Before the data from the ALP questionnaire could be assessed in terms of mean scores or group differences on accumulated loss, it was necessary to determine whether there was any evidence within the data from this questionnaire of the existence of this phenomenon. As stated above, factor analyses were used for this purpose.

The results of the exploratory factor analyses on the data from the ALP questionnaire do not always supply clear factors. However, comparisons of the factors found through both methods of rotation (orthogonal and oblique) and using the data from the whole sample, as well as data from each group of nurses, reveal that there is much similarity.

A five-factor, varimax analysis of all 91 items and using data from the whole sample accounted for a total of only 29.8 percent of the common variance (see Appendix VIII). This suggests that the questionnaire is addressing a varied group of constructs. The five factors which were produced could be described as being related to:

- 'boundaries and ideals vs reality',
- 'avoidance/distancing reactions',
- 'confidence in leadership and feeling rewarded for work',
- 'personal attitudes and self-care' and
- 'dread of pain from cancer'.

It can be seen that there is some similarity to the five basic characteristics proposed by Adams et al. (1991), which are 'lack of closure', 'dying and death concerns', ideals vs

reality incongruity', 'identification-distancing', and 'diminished boundaries'. There are, however, some obvious differences.

After attempts to improve the factor model by reducing the number of items, as explained above, five-factor varimax analysis using 35 items and data from the whole sample produced results as seen in Table 7.1. This analysis produced one large factor, accounting for 19.8 percent of the common variance, which included items related to four of the five characteristics of Accumulated Loss Phenomenon (Adams et al., 1991) (the exception being 'dying and death concerns'). The other four smaller factors accounted, in total, for an additional 27.2 percent of the variance and were related to:

- personal attitudes and caring for one's body,
- feeling rewarded and valued,
- feeling overburdened and
- crying in response to stress.

Again, only 47 percent of the common variance is accounted for. This suggests that even within this much reduced group of items, there may be several concepts or ideas which are being addressed. The results using the same 35 items and the 5-factor varimax process with the data from each nursing group can be found in Appendices IXa, IXb and IXc. When the analysis was carried out to find factors for which the eigenvalue was greater than one, using the same 35 items and data from the whole sample, nine factors emerged, accounting for a total of 60.8 percent of the variance. Notwithstanding the skewed nature of the data used, and the resulting need for a cautious approach to these results, this too may suggest that even within the 35 items, there are several concepts being addressed.

Although the meaning of factors emerging from the analyses is not always clear, there is a tendency for certain sets of items to group in every analysis. The 4 factors common to most of these analyses relate to a) the 'setting of boundaries' and 'the conflict of ideals vs realities' (see Factor 1, Table 7.1), b) 'the effect of work on personal attitudes and self-care' (Factor 2), 'feeling rewarded, acknowledged and respected' (see Factor 3) and 'avoidance and distancing reactions' (see Factor 4). 'Crying as a response to stress' is Factor 5 in this analysis, but is a clear factor in only some of the other analyses. These



factors are similar in content to those found using all 91 items in the scale (see previous page), with the exception of factor five.

Table 7.1: 5-Factor Analysis of 35 items (data from whole sample)

| <b>FACTOR 1</b> (19.8% of the common variance) - setting of boundaries and ideals vs realities | Loading | Statements which loaded .5 or greater on a factor   |
|--|---------|---|
| ALP 51   | 0.682   | I think about patients/families when I leave work   |
| ALP 52   | 0.651   | I have difficulty leaving work on time  |
| ALP 59   | 0.630   | I have difficulty in letting go of events at work and becoming involved in something after work |
| ALP 50   | 0.618   | I dream about work situations   |
| ALP 10   | 0.605   | I am stressed because I expect too much from myself   |
| ALP 11   | 0.599   | I am bothered by my feelings of inadequacy  |
| ALP 60   | 0.594   | I find my work interferes with my relationships with others                                     |
| ALP 53   | 0.593   | I skip lunch or breaks to do my work better   |
| ALP 47   | 0.581   | I am bothered by the lack of time to grieve after a patient's death                             |
| ALP 13   | 0.577   | I feel guilty when my daily work ideals are not achieved  |
| ALP 12   | 0.575   | I struggle with the conflict between ideals and reality, theory and practice                    |
| ALP 62   | 0.505   | I feel work-related stress affects my family relationships                                      |
| <b>FACTOR 2</b> (11.5%) - effect of work on personal attitudes and self-care                   |         |   |
| ALP 85   | 0.777   | I find this work experience makes me 'live for the day'   |
| ALP 86   | 0.758   | I find this work experience makes me be more positive and outgoing                              |
| ALP 87   | 0.665   | I find I make more short term goals   |
| ALP 84   | 0.626   | I care for my body differently since working with patients who are seriously ill or dying       |
| <b>FACTOR 3</b> (5.9%) - feeling rewarded, acknowledged and respected                          |         |   |
| ALP 17   | 0.855   | I feel rewarded and acknowledged for my work by my co-workers                                   |
| ALP 18   | 0.756   | I feel rewarded and acknowledged for my work by my Head Nurse                                   |
| ALP 16   | 0.756   | I feel rewarded and acknowledged for my work with patients/families                             |
| ALP 71   | 0.631   | I feel valued, respected and supported by my co-workers   |
| <b>FACTOR 4</b> (5.1%) - avoidance and distancing reactions                                    |         |   |
| ALP 23   | 0.723   | I feel impatient with over-grieving families  |
| ALP 24   | 0.616   | I find myself steering conversations with patients/families to stay on superficial topics       |
| ALP 37   | 0.591   | I dread admissions for fear of bonding with them  |
| ALP 45   | 0.535   | I feel overwhelmed by patient/family needs  |
| <b>FACTOR 5</b> (4.7%) - crying as a response to stress  |         |   |
| ALP 76   | 0.769   | I am able to cry in times of stress   |
| ALP 77   | 0.765   | I find that crying helps with stress  |

To check for group differences, Pearson Chi-Square test for association was carried out on all ALP items using the crosstabs selection from the SPSS programme. In order to ensure that cells had sufficient numbers for this test, scores were recoded to eliminate neutral responses and to combine 'agree/strongly agree' and 'disagree/strongly disagree'.

The results on those ALP items which show a significant relationship between nursing group and response are given in Table 7.2. To interpret these results further, a series of two-by-two crosstabs, using pairs of nursing groups, were carried out on each of the ALP items shown in Table 7.2 to determine where significant differences existed among the three groups.

Table 7.2: Accumulated Loss Phenomenon items showing significant association between clinical group and response (all three groups)

| Item No | Statement   | Chi-Sq Stats<br>(Degrees of Freedom<br>=2) |
|---------|---|--|
| 6       | I like to be with patients when they die  | 16.87, $p<0.001$                           |
| 9       | I am aware of the hope of patient/families to have a good death                           | 10.49, $p<0.01$                            |
| 16      | I feel rewarded and acknowledged for my work with patients/families                       | 26.46, $p<0.00001$                         |
| 17      | I feel rewarded and acknowledged for my work by my co-workers                             | 6.56, $p<0.05$                             |
| 19      | I expect more support than I get from members of other disciplines                        | 18.90, $p<0.0001$                          |
| 20      | I feel confident with our nursing leadership  | 17.55, $p<0.001$                           |
| 21      | I feel confident with our medical leadership  | 37.66, $p<0.00001$                         |
| 34      | I feel uncomfortable and inadequate with confused patients                                | 22.36, $p<0.0001$                          |
| 41      | Often I don't recognise bereaved families when I see them later                           | 17.07, $p<0.001$                           |
| 42      | If so (If yes to 41), this makes me feel guilty   | 21.02, $p<0.0001$                          |
| 44      | I address a patient by a name belonging to a former patient who died                      | 13.45, $p<0.01$                            |
| 47      | I am bothered by the lack of time to grieve after a patient's death                       | 6.75, $p<0.05$                             |
| 51      | I think about patients/families when I leave work   | 8.71, $p<0.02$                             |
| 53      | I skip lunch or breaks to do my work better   | 11.49, $p<0.01$                            |
| 57      | I call in sick when stressed or fed up  | 11.34, $p<0.01$                            |
| 63      | I discuss work-related issues with friends and family                                     | 9.04, $p<0.02$                             |
| 64      | I talk about death more with friends and family   | 8.11, $p<0.02$                             |
| 66      | Most of my friends are people I work with   | 6.31, $p<0.05$                             |
| 67      | I enjoy investing in new staff  | 6.89, $p<0.05$                             |
| 69      | I feel loss of staff as much as death of a patient  | 17.06, $p<0.001$                           |
| 70      | I feel I have a closer relationship with co-workers here than in previous jobs            | 25.25, $p<0.01$                            |
| 72      | I value, respect and support my co-workers  | 7.03, $p<0.05$                             |
| 73      | I think about getting cancer  | 20.29, $p<0.0001$                          |
| 74      | I dread disfigurement from cancer   | 18.72, $p<0.0001$                          |
| 77      | I find crying helps me with stress  | 7.05, $p<0.05$                             |
| 84      | I care for my body differently since working with patients who are seriously ill or dying | 10.02, $p<0.01$                            |
| 85      | I find this work experience makes me 'live for the day'                                   | 10.05, $p<0.01$                            |
| 86      | I find this work experience makes me be more positive and outgoing                        | 8.53, $p<0.02$                             |
| 87      | I find I make more short term goals   | 6.80, $p<0.05$                             |
| 88      | The rewards of my job outweigh the disadvantages  | 11.11, $p<0.01$                            |

Results of the 2X2 crosstabs testing may be found in Appendix X. These data suggest that, within this sample of nurses, palliative care nurses are more likely to think about

getting cancer and dread disfigurement from cancer. More of the palliative care nurses feel that they have closer relationships with their co-workers than they had in previous jobs. They feel rewarded and acknowledged by their co-workers, are more likely to feel respect and support for their colleagues and are happier with the support received from members of other disciplines. Although, in this sample, it is the palliative care nurses who are most likely to feel that the rewards of their job outweigh the disadvantages, it is noteworthy that 73 percent of the overall sample felt this way. More of the palliative care nurses feel confident with their medical leadership. The strength of palliative nurses' perceptions of support, leadership and job satisfaction is noteworthy and may be related to the fact that a larger percentage of this group are part-time workers. The finding may also, however, reveal a real difference in levels of organisational support available to palliative nurses when compared with the other two groups.

In this sample, psychiatric nurses feel less rewarded and acknowledged for their work, have less confidence in their nursing leadership, and expect more support than they get from members of other disciplines. They are more likely to call in sick when stressed or fed up and, like palliative care nurses, feel that losing a staff member may be as difficult as a patient death.

Psychiatric nurses' friends are more likely to be co-workers and their work experience is less likely to make them take better care of their bodies. Psychiatric nurses feel more comfortable and adequate in dealing with confused patients and are less likely to discuss death with their family and friends. General nurses are more likely to skip lunch or breaks to do their work better, are more likely to discuss work-related issues with family or friends and are least likely to enjoy investing in new staff.

Both palliative and general nurses appear to differ from the psychiatric nurses insofar as they have a greater awareness of the wishes of patients/families for a good death, like to be with patients when they die, think about patients/families when they are off-duty and feel guilt when they fail to recognise families of past patients who died. They feel rewarded and acknowledged for their work and find that work tends to make them more outgoing and positive. Palliative and general care nurses are more bothered by the lack of time to grieve after a patient death but 32 percent of the psychiatric nurses also agreed that this is a problem.

Because of the lack of evidence to support the existence of a specific phenomenon of accumulated loss as measured by this questionnaire, total or mean scores for the whole questionnaire were not considered to be relevant.

### 7.2.3 - Comparison of Burnout and Accumulated Loss Phenomenon (ALP)

There are significant positive correlations (0.474,  $p < 0.001$ ) between the burnout element of 'emotional exhaustion' (EETOT) and the ALP items (ALPEE) which were deemed to be similar (see Data Analysis above and Appendix XI) and between the burnout element of 'depersonalisation' (DPTOT) and the corresponding ALP items (ALPDP, see Appendix XI) (0.390,  $p < 0.001$ ). No significant correlation is evident between the burnout element of 'personal accomplishment' (PATOT) and the corresponding ALP items (ALPPA, see Appendix XI). This may be because chosen items from the Accumulated Loss scale were addressing different experiences or concepts. Table 7.3 shows the Spearman correlation statistics for these groups of items. It is important to note the significant correlation between all ALP item groups used and the 'emotional exhaustion' and 'depersonalisation' totals from the burnout scale. These figures reveal considerable overlap between the two scales in terms of what is being measured.

Table 7.3: Spearman Correlation statistics for comparison of Burnout Maslach Burnout Instrument (MBI) and Accumulated Loss Phenomenon (ALP) - (N = 271)

|                                       | ALPEE - Accumulated Loss items considered similar to emotional exhaustion items from MBI | ALPDP - Accumulated Loss items considered similar to depersonalization items from MBI | ALPPA - Accumulated Loss items considered similar to personal accomplishment items from MBI |
|---------------------------------------|--|---|---|
| EETOT - emotional exhaustion (MBI)    | 0.474 sig 0.000  | 0.280 sig 0.000   | 0.429 sig 0.000   |
| DPTOT - depersonalization (MBI)       | 0.345 sig 0.000  | 0.390 sig 0.000   | 0.257 sig 0.000   |
| PATOT - personal accomplishment (MBI) | -0.214 sig 0.000   | -0.253 sig 0.000  | -0.056 NS   |

If the accumulated loss scale is measuring a phenomenon similar to burnout, then negative correlations between personal accomplishment on the Maslach Burnout Instrument (PATOT) and all of the items from the accumulated loss scale which were deemed to be similar to Burnout items (ALPEE, ALPDP, ALPPA) are as expected. This is because high burnout is said to be demonstrated by high scores on emotional exhaustion and depersonalization and low scores on personal accomplishment.

### **7.3 - Discussion**

#### **7.3.1 - Effects of Working with the Dying**

Any discussion of effects of working with the dying must acknowledge the difficulty in separating specific causes of any effect. Some of the effects of this work are no doubt attributable to multiple causes and not necessarily only to the patient death. This study has not looked at the effects of stressors outside the workplace and nurses do talk about the accumulative effects of different stressors which may be work- or home-related.

Patient death and nursing the dying have been shown in this study to be stressful parts of the occupation of nursing (see 4.2.2.1 and Chapter Six). This stressful work is reported to have a number of effects on the nurses' well-being, personal and professional attitudes and relationships with others. The emotional nature of the experience is underlined in this study by the fact that 'sadness' and 'relief for the patient' were given by more than 80 percent of the sample as the two main effects they felt after patient death. The findings support previous work by many researchers, including Vachon (1987) and Field (1989).

The prominence of nurses' sense of 'relief for the patient' raises some questions. For example, is that relief always for the patient, or in part, is it the nurse feeling relief that this stressful event has finished? Inability to meet patients' needs has been shown, in this sample, to be an important stressor (see 4.2.2.i) and there is evidence that nurses are sometimes unhappy about the kind of care given prior to death (see Chapter Six). This suggests that, in some cases, feelings of relief following patient death may be felt so strongly because patients are still seen to be suffering prior to death, in spite of modern understanding of palliative care and/or because nurses have been unable to achieve their ideal of the 'good death' for their patient.

The qualitative data provide ample evidence that the effects of this work are not restricted to the immediate feelings of the nurse. Disturbed sleep patterns, emotional upset and problems with relationships are serious effects which have been reported by the nurses. These effects also appear to impact on families of nurses who report marital discord resulting from the nurse having 'nothing left to give' after work. If nurses are unable, as they report, to share their work-related worries and emotions with family, they are unlikely to be able to replenish their coping resources at home and, if there are also problems within the home, the impact on the level of stress experienced by the nurse may be two-fold.

Further, these effects are likely to be costly to employers in terms of efficiency, absenteeism and staff turnover. There is likely to be an effect on patient care but that is difficult to assess in a self-report study. When nurses were asked about this, they rarely admitted any such effect and assured the researcher that the patient always 'came first'. A more focused ethnographic/observation approach would be required to investigate the effect on patient care.

### 7.3.2 - Accumulated Loss Phenomenon

Data from the ALP questionnaire provide only limited support for the concept of the Accumulated Loss Phenomenon (Adams et al., 1991). The original paper made certain assertions on the basis of a 5-Factor varimax analysis. Results of a 5-Factor varimax analysis of the data in this study (using all 91 items of the scale) can be seen in Appendix VIII. Adams et. al. proposed that the five characteristics of ALP were found to be 'lack of closure', 'dying and death concerns', 'ideals vs reality incongruity', 'identification-distancing' and 'diminished boundaries'. There is evidence in the data from this study of a clear factor relating to 'identification-distancing'. The factor relating to 'diminished boundaries' usually includes the items about 'ideals vs reality'. The data do not support the presence of the other factors. Further, the factors which are produced represent a relatively small portion of the variance, raising the suggestion that there are several ideas being addressed within this scale.

Adams et al. used their questionnaire only with hospice carers (n=100). They acknowledged the need to investigate other groups of carers as has been done in this study. Data from the three groups of nurses does not support the idea that Accumulated Loss Phenomenon, if it exists as a distinct phenomenon, is found only among those who care for many dying patients. Factor analysis on data from the three groups shows the same lack of clarity in factors and insufficient difference among the groups to support the idea that any one group stands out from the others, even in terms of those factors which are relatively clear.

The pattern of group differences in response to individual items does not support the idea of a phenomenon unique to an individual group. This is particularly evident from an examination of the items which do not show group difference in response. For example, it is clear that nurses from the three groups do not differ significantly in their difficulty with setting boundaries between home and work, in their use of avoidance/distancing behaviour, or in their concerns about ideals vs reality in their working practice. There is no significant difference in numbers reporting a sense of accumulated losses at work and palliative and general nurses both report being concerned about the lack of time to grieve after patient death. Even within the psychiatric group, for many of whom patient death is a very infrequent experience, 32 percent report finding this a problem. This reflects the portion of the group who work in elderly care where patient death is a more frequent occurrence and where, in some respects, nurses face the same problems as those working in general wards.

However, some accumulative effects of experiencing multiple patient death have been evident in the qualitative data (see 7.2.1.ii). In talking about the effects of working with the dying, nurses have reported effects which they perceive to be related to long-term work with dying patients and to multiple or frequent patient deaths. They have spoken about their blunted emotions, their loss of a sense of humour, their inability to face another day of patient death, their inability to support colleagues because of their own feelings of being overloaded with emotions, their feelings of being burnt out and exhausted and the lack of opportunity for closure. The qualitative data suggest that this may be the best manner in which to investigate further the possible existence of a particular phenomenon of accumulated loss. At very least, qualitative methods are indicated as a necessary accompaniment to any further investigation with a new quantitative instrument.

### 7.3.3 - Comparison of Burnout and Accumulated Loss Phenomenon

The results of the Spearman Correlation tests suggest that whatever is being measured by the ALP instrument may be related to burnout, as described by Maslach and Jackson, (1981). While the correlations are relatively small, coupled with the information from the exploratory factor analysis, they provide some support for the idea that this is burnout among nurses rather than a unique phenomenon as described by Adams et al. (1991). This may be burnout as an effect of accumulated or multiple loss. However, it is also worth considering that a nurse who is suffering from burnout, hence finding his/her coping resources inadequate, may be more susceptible to adverse effects of accumulated loss. Much more investigation is required before a direction of influence could be proposed.

It is acknowledged that any Factor Analysis on these data can only be exploratory because of the skewed nature of the data from this sample. This raises the question of suitability of the use of factor analysis in the original study. However, no information is available on the nature of distribution of data collected from the original sample studied by Adams et al. (1991). It is clear however, that on the basis of this sample, three times as large as the original sample and taken from three groups of nurses for comparison, the existence of a unique phenomenon as described by Adams et al. is in some considerable doubt. If this concept is to be investigated further through quantitative methods, the investigative instrument requires much further work.

## 7.4 - Summary

In confirmation of previous research, qualitative data reveal a wide range of effects on nurses which they perceive to be related to workplace stress associated with caring for the dying. These effects include emotional strain, sleepless nights, marital discord, changes to personal and professional attitudes and loss of a sense of humour.

In a new exploratory investigation of the proposed accumulated loss phenomenon, the investigative instrument has been shown to require much further work if this concept is to be researched through quantitative measures. An exploratory factor analysis of the quantitative results shows little support either for the existence of such a phenomenon or



for the contention that the phenomenon is suffered primarily by hospice workers. However, the qualitative data show some evidence of the accumulative effects of this work and suggest that a more appropriate method of investigation would be qualitative, in-depth interviews which should, at the very least, be used alongside a quantitative measure. When compared with results of the Maslach Burnout Instrument (1981), there is evidence of considerable overlap between the two scales, suggesting that what has previously been called the accumulated loss phenomenon may be burnout resulting from the effects of an accumulation of death-related loss.

## **CHAPTER EIGHT**

### **8 - Overview, Implications and Methodological Evaluation**

#### **8.1 - Introduction**

This study, using both quantitative and qualitative methods, broadly aimed to investigate the relationships between stress, death attitudes and the experience of patient death in three groups of nurses, from palliative, psychiatric and general clinical areas. Nurses from these three areas of work tend to have different experiences of patient death, both in terms of the frequency with which the experience is encountered and the organisational culture within which the nurses work. These differences allowed meaningful comparisons to be drawn across the three groups on several aspects of the study, as discussed in previous chapters and below. The full list of hypotheses and research questions is found on pages 49-50.

The study aimed to assess levels of psychological well-being and burnout, comparing the three groups of nurses. Also examined were group differences on ratings for the importance of sources of stress, the relative importance of patient death as a stressor and coping strategies used and found most effective to deal with work-related stress. These findings have provided a current picture of sources of stress and levels of well-being among these nurses, updating and supporting other literature already discussed. Further, as discussed below, they provide a contextual background for the more novel study of death attitudes.

This research has investigated, for the first time, fear of death in nurses in the United Kingdom in the attempt to add to the very limited knowledge of how personal fears may be affected by clinical experience of patient death and dying. In order to put nurses' reported levels of fear of death into perspective, a study of fear of death within a general population sample has been carried out, again for the first time in this country. The findings are, in part, supportive of some previous research with medical students but, in addition, they provide substantial new information about fear of death in nurses.

To add to the understanding of stress associated with patient death, the study also investigated nurses' perceptions about their abilities to cope with death and dying issues, using quantitative measures. The work incorporated statistical testing to determine reliability figures for the two scales (Coping with Death Scale, Bugen, 1980-81; Death Self-Efficacy Scale, Robbins, 1992) which have not been used previously in the United Kingdom. As above, these are new findings, allowing a statistical comparison of groups of nurses, in terms of the perceptions of their own competence to deal with death and dying issues. Further, interviews and diaries provided a rich source of data about nurses' perceptions about which elements of the experience of patient death create the greatest potential for an appraisal of stress.

Finally, the rich and expressive qualitative data provided information about what nurses perceive to be the personal impact of working with dying patients and their families. In an area where there has been very little previous research, a quantitative measure was also used in an attempt to assess the credibility of a proposed phenomenon known as accumulated loss phenomenon, said to be the result of working with many dying patients. To make this assessment, findings from this study, using the original quantitative measure for accumulated loss (Adams et al., 1991) were compared with those from the burnout scale (Maslach and Jackson, 1981). This work, using data from a sample of 300 nurses from three clinical areas, is a considerable extension of the original study which used data from 100 hospice nurses.

Chapters Four to Seven contain the detailed accounts and discussion of the findings in each of the four areas of the research. In the following section, the results from the four facets of the study will be integrated to form 'profiles'. These profiles will highlight and combine the key findings about the nursing experience of stress and patient death for these nurses, as a whole sample and for each of the three groups. It is intended that these profiles will allow the reader to compare more easily the different group experiences and perceptions and to develop greater understanding of this complex occupational stressor.

## **8.2 - Overview**

### **8.2.1 - The Overall Sample of Nurses**

While the sample was, by necessity, a volunteer sample, with the accompanying possibility of inherent bias, the findings suggest that the sample was reasonably representative of the wider population of nurses, in terms of both levels of reported psychological well-being and sources of stress. Mean scores for the GHQ-12 (13.80, n=302) are similar to those found by Spelten et al. (1993) within a large sample of nurses. Further, the percentage of this sample (23.4 percent) scoring higher than five, using the 'caseness' scoring method, is lower than that reported by Tyler and Cushway (1992), which was 29 percent. As in previous research (Tyler et al., 1991; Tyler and Cushway, 1992), there is no significant difference across the three groups of nurses on levels of psychological well-being (GHQ-12). Patient death was rated seventh on the list of 24 potential stressors. This, too, agrees with many previous studies, as earlier acknowledged, which report death and dying issues to be important stressors for nurses. However, while these nurses perceive patient death to be stressful, it is not the most important stressor for any of the groups in this sample. This would seem to indicate that the sample did not have a uniquely high perception of the importance of stress associated with patient death.

The similarity of these findings to those of previous researchers and the relatively moderate way in which patient death is rated as a stressor are important features because they lend credibility to the findings in the more novel aspects of this study, related to death attitudes. Previous researchers have considered psychological well-being to be one of the main determinants of death anxiety (Lonetto, 1986). On that basis, if levels of psychological well-being are not abnormally low within this sample of nurses, it follows that levels of fear of death should not be abnormally high within this sample. While GHQ did correlate negatively with fear of death in this sample, coefficients were small and it is acknowledged that there is a need for much further research in the area of death attitudes. However, it can be argued that these findings provide a sound basis for that further research.

Within the overall sample of nurses, several important features have emerged. The five most important sources of stress at work were reported to be workload, inadequate staffing, difficult/violent patients, inability to meet patients' needs and inadequate

understanding/support from senior staff. Patient death followed in seventh place as a substantial source of stress for nurses. As stated in Chapter Four, these findings are broadly similar to previous studies. The findings emphasise the apparently perpetual nature of the nurses' problems related to workload and staffing.

While not regarded as the most important source of stress, nurses in this sample tended to regard the stress associated with patient death as different from that associated with other areas of work (4.2.3). The reasons for this view were largely related to the emotional nature of the work and the emotional impact on the nurse. Additionally, qualitative accounts highlighted the importance of getting the care right and the lack of opportunity for a second chance or to make corrections to mistakes (4.2.3). There appear to be several factors involved in determining what made the nurse appraise an experience of patient death as stressful (6.4.4). These included identifying with the patient, the duration of the period of nursing, conflicts with other medical personnel about treatment, previous experience and the specific nature of the death. Aside from the emotional factors and personal grief resulting from nurse/patient relationships which ended in loss or bereavement, the majority of the factors appeared to relate in some way to providing the ideal of the 'good death' and maintaining certain professional standards. When, for whatever reason, it was not possible to achieve those aims, nurses perceived the experience as more stressful. This accords with much of the literature on the good death which acknowledges nurses' stress resulting from their inability, for whatever reason, to meet their goals of care for the dying (McNamara et al., 1995).

Social support was reported to be the most effective and most widely used coping strategy, again in accord with previously reported and acknowledged research (4.2.4). In this sample, there appeared to be a high level of dependency on colleagues for this support. Nurses from all three groups reported some difficulty with finding adequate support from colleagues, either because of lack of time and/or opportunity to meet, the inadequacy of staff meetings, or because colleagues were already overburdened. Further, it appears that many nurses are unable to find support from families because of the need to separate work from home and/or because their work-experiences are too traumatic for their families to deal with (4.2.4 and 7.2.1.ii). These findings suggest that there is a need for consideration of how nurses' needs for social support may be met more adequately.

Large numbers of the sample report the use of avoidance/distancing (60 percent of the sample) and techniques such as physical exercise to reduce tension (50 percent) to alleviate work-related stress. In contrast to other studies (Schaefer and Peterson, 1992; Ceslowitz, 1989), there was little evidence in this sample of the use of problem-solving approaches to coping. Few nurses acknowledged the use of special coping strategies to deal with patient death. It is acknowledged that these two latter findings may represent a methodological weakness in the question used for data gathering. Nurses may use problem-solving approaches which they do not perceive as coping strategies and may be reluctant to disclose special coping strategies in response to questionnaire. In-depth interviewing which provided more time for reflection on this question may have produced different findings.

For the first time, the question of fear of death in nurses and in a general population sample within the United Kingdom has been addressed (Chapter Five). Three hypotheses related to the overall sample were under test. Contrary to the hypothesis that nurses' scores would be lower than the general population, as a whole sample, nurses' scores on fear of the process of one's own death were significantly higher than those of the general population sample. The hypothesis that low levels of psychological well-being (GHQ-12) would correlate with high levels of fear of death was accepted but coefficients were low. Similarly, the hypothesis that frequency of patient death would correlate negatively with fear of death was accepted but, again, with low coefficients.

Greater age was related to lower intensity of fear of death in the general population sample but when the portion of the sample aged over 65 years was removed, the correlation was not significant. Within the nursing sample (all aged 65 years or under) there was a weak negative correlation between age and intensity of fear (5.2.1.iii). These findings suggest that it may be the experience gained with age in the nursing population which influences fear of death, rather than age per se. This importance of clinical experience as an influence on fear of death is supported by the finding that 'frequency of patient death experienced' also correlates negatively (with low coefficients) with intensity of fear. The influence of training on fear of death is also of interest as there were significant differences on all intensity of fear questions between those who had/not had extra training in some aspect of care for the dying and their families. Those who had extra training reported lower levels of fear (5.2.1.iv).

These findings support the concept of a relationship between fear of death and the experience of being a nurse. Differences between the three groups of nurses were also found and will be discussed in the relevant sections below. Briefly, the results show palliative nurses reporting lower levels of fear and general nurses showing higher levels of fear. From the combined data, one may conclude that some clinical experience may increase fear associated with death and dying but increasing clinical experience may actually decrease fears. However, another factor in the relationship between experience of death and fear of death may be the kind of death which is experienced in terms of 'good' death or 'bad' death. The data suggest that the palliative group may have more frequent experience of 'good' death than the general nurses whose experience may more often be perceived as 'bad'. This may affect the extent and direction of any influence on fear of death which those nurses may feel. The data clearly suggest that the contention by Firth-Cozens and Field (1991), that experience of death and dying may reduce levels of fear of death, does not sufficiently explain the complexity of the relationship between experience and fear (see Theoretical Implications, below).

Some nurses from general and palliative areas of nursing reported that their fears about death and dying did increase when they had to cope with many deaths in a relatively short period of time - an infrequent experience for many psychiatric nurses (7.2.1.ii). Further, several nurses from all three groups expressed fears which they said had been exacerbated by their work experiences. These included fear associated with certain illnesses such as cancer and motor-neurone disease, fears about the kind of care they might receive when they were elderly or near death, and fears about the consequences of their own death for their families, especially children.

There are also signs in the data, both quantitative and qualitative, that substantial numbers of nurses from all three groups perceive some inadequacy in their ability to deal with death and dying issues (Chapter Six). At least in part, this inadequacy appears to be related to training because approximately half of this sample perceived their training to have been inadequate to deal with communicating and caring for the dying and/or coping with relatives of the dying and/or dealing with their own feelings about patient death (6.2.4). Further, there was a significant difference in mean scores on both coping with death and death self-efficacy measures, between those who had or had not had extra training to deal

with palliative care and/or caring for the dying and/or bereavement counselling. Those having extra training reported higher self-efficacy. Some nurses who had received special training to cope with some aspects of caring for the dying expressed the view that such training should be available at an earlier stage of the nursing career. Other nurses complained of the lack of availability of such training.

Throughout the sample, there was considerable emphasis in self-reports of nurses being affected, often adversely, by their work, especially the work with dying patients and their relatives (Chapter Seven). Effects ranged from fatigue and 'feeling burnt out' to marital problems caused by the nurse 'having nothing left to give' when s/he went home to the family. Nurses reported the loss of a sense of humour, having difficulty keeping things in perspective and having to guard against thinking that everyone is ill or that all elderly people are infirm. However, as in previous research (Vachon, 1987; Field, 1989), there was also a strong seam of evidence that nurses from all three areas gain considerable satisfaction from their work, even in very difficult circumstances. Seventy-three percent of this sample reported that the rewards of their job outweigh the disadvantages (7.2.2). In response to an open question (Appendix IIj) about the most rewarding aspects of their work, 272 nurses chose to write responses, 157 of which referred to some aspect of giving good care to the patient (4.2.2.ii). For example, terms used included providing holistic care, being able to control symptoms, helping the patient to have a good death and achieving a successful outcome for the patient. It appears that, not only do nurses feel most rewarded and fulfilled, but they suffer less stress when they are able to accomplish their nursing goals of holistic care and provision of 'the good death'.

When the three groups are considered individually, it can be seen that while there are many common issues, several factors appear to separate the groups. The key findings pertaining to each of the three groups will be discussed below.

### 8.2.2 - Palliative Care Nurses

The heavy emotional and professional demands and the effects of palliative care work are evident in the data which indicate that this group reports more stress from dealing with relatives and from the need to give of themselves on a continuous basis (4.2.2.i). So, too, palliative care nurses are more likely to think about getting cancer and the effects of cancer



(7.2.2). However, in many ways, data from the palliative care nurses seem to reflect their training and experience as well as the differences in organisational culture or ethos which may be found between palliative care units and those of psychiatric or general nursing care.

While palliative care nurses may carry heavy burdens, quantitative data indicate that they are also more likely than the other two groups of nurses to perceive their working conditions and support systems to be adequate (7.2.2). This group of nurses seems to experience less stress from the shortage of resources and staffing on their units, the level of control over decision-making processes or the lack of opportunities for their own personal growth (4.2.2.i). They appear to be happier with their leaders and with their colleagues (7.2.2).

It was hypothesised that palliative care nurses would have lower levels of fear of death than the other two groups. This hypothesis was accepted in part. Palliative care nurses report lower levels of fear only on fear associated with caring for their dying patients (5.2.1.i). In contrast to the other two groups, when compared with the general population sample, palliative care nurses report less fear associated with the death of a close other (5.2.3). Although many of these palliative nurses do report that their training was inadequate to prepare them for some aspects of their work, this group also reports levels of perceived self-efficacy in dealing with death and dying which are higher than the other two groups (6.2.1), supporting the hypothesis which was under test (See pages 49-50). It is perhaps not surprising that, when compared with general and psychiatric nurses, significantly more palliative care nurses agree that the rewards of their job outweigh the disadvantages (7.2.2).

The data reveals that this group of nurses, trained and experienced in the care of dying patients and their families, have high ideals related to the kind of care which they should give to their patients, who are, virtually without exception, terminally ill. They strive to achieve the 'good death' - pain and symptom-free, with the family present and the patient at ease physically and emotionally (6.4.4) - and generally appear to perceive that they are capable of providing this good death, given the appropriate time and the cooperation of other disciplines. They do express some concerns about nurse/doctor conflicts, usually about pain control, and they do have concerns about the effects of recent policy changes

which have resulted in faster patient turnover and less time to prepare patients and families before death (6.4.4 and 7.2).

Although the quantitative data did not support the concept of a unique phenomenon of accumulated loss, there is evidence from some members of the palliative group that nurses may be adversely affected by the accumulative effects of working with many dying patients (7.2.1.ii). This group, not surprisingly, reported the highest incidence of patient death (Chapter Three). In interviews, palliative care nurses described their feelings about having to push experiences to the back of their mind to avoid being overwhelmed, about going into “auto-pilot” in order to cope when one death follows quickly after another, taking time off because they could not face another day of patient death and about having so many difficult experiences and emotions to cope with that they were unable to be supportive to other colleagues (7.2.1.ii).

This sample differed from the psychiatric and general nursing samples in that there were greater numbers in the top age ranges (41 to 65 years), more of this group worked part-time (see below), they had all had some training specifically related to palliative/terminal care and nearly one third of the group worked within the community. The potential effects of these factors on the data have been acknowledged previously. For example, age (with relevant experience) and training appear to have been factors in findings related to fear of death and perceived ability to cope with death and dying. The numbers of part-time workers may account for the relatively low levels of emotional exhaustion among palliative care nurses (when compared with psychiatric nurses). This suggests the need for a further study investigating only nurses who work full-time.

### 8.2.3 - Psychiatric Nurses

Although the levels of reported psychological stress were similar across the three groups, the psychiatric group scored significantly higher on the burnout (MBI) element of emotional exhaustion (4.2.1). One factor which set this group apart from the other two groups was the very high proportion of the psychiatric group who worked full-time (94 percent as opposed to 70 percent of the palliative and 80 percent of the general nurses (Chapter Three). This factor may account, in part, for the burnout results. However, the

finding underlines the need to remember that, while terminal care is stressful work, there are other areas of nursing care wherein the staff are vulnerable to serious effects of stress.

While the psychiatric nurses in this sample had fewer patient deaths with which to contend, they reported more stress associated with the shortage of resources in their units, being asked to do work outside their competence, a lack of control over decisions and a lack of support from superiors (4.2.2.i). For these psychiatric nurses, some important stressors were very specifically related to their particular kind of client. Qualitative data (4.2.2.ii) indicated that for those in acute care wards, the level of constant observation required and the tension experienced in their units were significant stressors. In elderly care wards where patients were long-term dementia sufferers, nurses reported some difficulty in finding job satisfaction because of the lack of a 'normal' patient/nurse relationship. Almost one third of the psychiatric group also reported great stress associated with the lack of opportunity for personal growth (4.2.2.i).

Recent organisational changes appear to have created problems for this sample of psychiatric nurses. The qualitative data (4.2.2.ii) includes several examples of nurses feeling isolated from the decision-making while still being expected to accept great responsibility and feeling that change was imposed without adequate consultation or resources to implement the changes. The nurses also perceived that recent policy changes were disadvantageous for patients who were sometimes released too quickly and, as a consequence, returned to hospital for a further stay.

It is worth noting that the mean scores of psychiatric nurses on fear of death did not differ significantly from those of the general population (5.2.3). Further, they felt at least as able as the general nurses to cope with death and dying issues (6.2.1). This finding may be related to the lack of experience of patient death which tests the skills to cope with the event. Nurses who have experienced a greater number of patient deaths may, through those demanding experiences, have learned to recognise their own inadequacies of skill. Nonetheless, a considerable number of the psychiatric group still reported that their training had not been adequate for some aspects of caring for dying patients and their relatives (6.2.4) and the data suggest that when patient death occurs, it is as stressful for psychiatric nurses as for any other (4.2.2.i).

For some psychiatric nurses, patient death is likely to involve violence, and/or sudden or unexpected death such as suicide. The repercussions for the nurses in these situations involved the added dimension of potentially being blamed for some aspect of the death (6.4.4). These findings highlight the need to consider the specific nature and consequences of patient death in psychiatric nursing.

Some nurses who were interviewed reported feeling let down and unsupported by management when dealing with traumatic deaths (6.4.4). This finding was supported by quantitative data which indicated that psychiatric nurses felt less confidence in their leaders and less support from members of other disciplines (7.2.2). When compared with the other two groups, these nurses also appear to be less likely to feel rewarded by their work or to develop a positive outlook on life because of their work experience (7.2.2).

This sample differed from the other two groups of nurses in terms of the balance of gender. Thirty-five males were included in the psychiatric nursing sample as compared with two in palliative and four in general nursing. Where this factor was considered to create a bias, as in the study of fear of death, the samples were filtered to account for this gender effect (Chapter Five). It would appear that there is some scope for greater comparison of psychiatric nurses with those of other clinical areas. The literature tends to provide comparisons of nursing groups which do not include psychiatric nurses, but as seen in this study, in many ways their needs and concerns are similar to those of other units. However, this study also highlighted the need to study death and dying specifically from the psychiatric nurses' perspective.

#### 8.2.4 - General Nurses

Among the general nurses, there were also some stressors which appeared to be much more important than within the other two groups. For example, general nurses not only report being understaffed in their units but also appear to have greater problems with incompetent or unqualified staff (4.2.2.1) and significantly fewer of this group enjoy investing in new staff (7.2.2). These nurses also expressed their feelings of a lack of support from members of other disciplines and differed from palliative care nurses in that they reported a lack of confidence in their medical leadership (7.2.2). More than a third of this group also reported severe stress from a lack of opportunity for personal growth

(4.2.2.i). These findings give the impression of a group of nurses who feel ill at ease with colleagues and with members of other disciplines. Given the importance of social support as a coping strategy (4.2.4), and the level of dependence on colleagues for this support, there are serious implications for nurses' well-being. This will be discussed below.

General nurses report levels of fear associated with the death of a close other which are higher than the other two groups of nurses (5.2.1.I) and levels of fear associated with the process of dying which are higher than those reported by the general population sample (5.2.3). In view of the relatively high rate of patient death which general nurses encounter in their work, this finding raises concerns for the well-being of both nurse and patient/family.

These concerns are accentuated by the finding that many of this sample of general nurses perceive themselves to be inadequately prepared to deal with death and dying issues (6.2.1). As was reported in 5.2.1.iv, there was a significant difference in fear of death scores between those nurses who had and those who had not had extra training to cope with death and dying issues, with those having extra training reporting less fear. Sixty percent of these general nurses believed that their training was inadequate to deal with some aspects of their work with dying patients and their families (6.2.4). On both coping with death and death self-efficacy measures, the general nurses' mean scores are lowest of the three groups and significantly lower than those of the palliative group. These findings suggest a need for much greater attention to death-related education and training for nurses.

In the qualitative data, the impression given by general nurses was that they have strong ideals of holistic care for all of their patients but that organisational changes and staffing policies have resulted in too little time to provide the psychological or emotional nursing which they believe their patients should receive (Chapter Four and Chapter Six). This situation appears to be compounded, in the case of dying patients, by the perception that the ward culture and attitudes of staff in general nursing units do not easily facilitate the provision of the 'good death'. Even though these nurses clearly wished to provide the same peaceful, symptom-free death for which palliative care nurses strive, they report a perception that, in general nursing wards, dying patients are sidelined and not given the attention that they deserve. The data suggest that this is perceived to happen because the

medical focus is too strongly aligned with cure, there is a lack of palliative care expertise, and/or because many personnel find it difficult to deal with patient death.

The combined findings, as they pertain to this group of general nurses, suggest that there is a distinct need for improved training for caring for the dying and that there is still, in the general nursing area, a need to improve care for dying patients for the benefit of both patient and nurse.

Of the three nursing groups, the general nurses had the highest percentage of nurses working in hospital units (92.9 percent as opposed to 75.8 percent of psychiatric and 4.5 percent of palliative) and contained twice as many nurses in the lower age bracket (under 30 years), although this proportion was still only one third of the general nursing sample. Some problems or concerns which appeared to be specifically related to these factors have been discussed, for example the relationship between age and fear of death and the perceived inadequacy of care for dying patients in general care units which is reported by this sample. The use of multivariate statistical testing would have allowed a greater investigation of the role of age in this research but was, as previously stated, disallowed by the skewed nature of some portions of the data.

#### 8.2.5 - The Findings in a Wider Context

The findings of the study might be viewed from a less reductionist perspective and considered in the light of other aspects of the modern nursing role. Recent sociological changes mean that three quarters of all Britons now die in institutions (Walter, 1996), the majority of those in hospital, rather than hospice (Llewelyn and Payne, 1995). As a result, many people reach established adulthood and may enter the nursing profession without any experience of death or dying. When a nurse begins work, s/he is faced with the potential of having to cope with the death of a patient and is totally dependent on whatever training has been given, whatever support may be available from more experienced staff and her/his own personal resources to cope with the first experience of death.

Using the Lazarus and Folkman (1984) framework, it may be argued that the novelty of the experience of death and dying would, for most nurses, increase the potential for an appraisal of 'threat'. The influence of novelty would be reduced as the nurse gains

experience of patient death. However, according to the Lazarus and Folkman (1984) framework, the perceived ability to cope with an event and coping strategies perceived available to the nurse are also crucial determinants of the kind of appraisal which results. If, as this study has shown, even experienced nurses perceive themselves to be inadequately prepared for the work and/or feel unsupported by colleagues and/or other disciplines, there is an increased likelihood that the nurse will experience stress while doing this work.

The lack of experience of death, coupled with great medical advances which often leave the layperson in awe of medical personnel, have meant that, once in hospital, the patient largely relinquishes control of his or her own destiny into the hands of 'the experts' (Walter, 1996). In hospices, the ideal is somewhat different, in that there is an attempt to allow, or even encourage, the patient to make decisions and to allow the patient to die as they would wish to die. This difference in ethos or philosophy of care of the dying may be part of the reason why many nurses in this sample believe that palliative units provide a better kind of care for dying patients.

The nursing role in palliative care extends beyond the patient and includes the care of relatives and families during the sometimes lengthy period prior to death and well after the event. Similarly, in general and even in psychiatric nursing, support and care for the relatives forms part of the expectation of what a nurse should deliver. The meaning and scope of holistic care appears to be ever widening. From data in this research, it seems that nurses accept the ideals and the responsibilities, yet feel inadequately prepared and supported to meet many of the ideals, particularly in terms of caring for the dying. Further, they are often obliged to work in conditions of staff shortages and resource deficiency. The general nurses, especially, seem to perceive a serious flaw in the care of dying patients within their nursing culture.

When one considers the findings from this study, for the overall group and for the three samples from distinct clinical areas of nursing, it is little wonder that, in their work, nurses perceive a disparity between demands and their resources to meet those demands and are reporting stress as a result (see also Fallowfield, 1991). If there is any interest in attempting to achieve better management of patient death (with less stress and negative outcome for the nurse), then it is vital to consider the implications of the findings in this

study. The practical and theoretical implications of these findings will be discussed below in 8.3.1 and 8.3.2 respectively. There are also methodological implications of some of the findings and these will be discussed in the Methodological Evaluation section, 8.3.3, which is followed by some suggestions for further research.

## **8.3 - Implications**

### **8.3.1 - Practical Implications**

Findings discussed in Chapters Four to Seven and above give rise to concerns and practical implications related to three broad areas. There is a strong sense from the data that nurses require considerable support to cope with their work and do not always feel that the support is available. Secondly, nurses appear to feel dissatisfied with some aspects of their training, especially when related to the care of the dying. General nurses appear to have relatively low perceived death self-efficacy. This is especially important when considered alongside the evidence in this study that clinical experience appears to have an effect on levels of fear of death and general nurses report higher levels of fear of death than the general population sample. Finally, there are several issues which relate to the nursing ethos or culture of care within which nurses work. These three areas will be discussed below.

#### **8.3.1.i - Coping**

Although the data reveals some frustration and discomfort with some aspects of the system within which these nurses work, there is a strong impression of nurses coping well with the heavy demands of their work. Nevertheless, this coping is often at considerable personal cost and throughout the data, both quantitative and qualitative, there is a powerful common theme which suggests that nurses would benefit from a more structured approach to the development and provision of coping skills and resources.

Nurses in this sample made several suggestions about how they believed their access to social support could be improved. These suggestions included the availability of someone who was available to talk to on a one-to-one basis when it was convenient for the nurse, work patterns which allowed nurses to meet during lunch and coffee breaks for informal



periods of sharing, and informal meetings which allowed nurses to verbalise their feelings and concerns, especially those related to death and dying. It was clear that, largely, nurses accepted the responsibility of finding their own sources of support but this was difficult when partners or families could not be relied upon for help.

While nurses should be encouraged to continue to develop their own methods of providing support to each other, it may be valuable for management to take a more structured approach to the provision of adequate social support for nurses, especially in light of the obvious importance of this coping strategy. The importance of having nursing teams which work together long enough to form cohesive and supportive bonds must be evident. Policy makers should be aware of the need for, and benefits of, supportive networks and, whenever possible, should build those networking opportunities into working practice for medical and nursing personnel.

The development of coping skills may be improved through a more thorough study of coping during nurses' years of basic training. Nurses are already taught to apply the problem-solving approach to the delivery of nursing care, through the use of the nursing process. However, there is little evidence in this sample of conscious effort to apply these ideas to dealing with stress. For nurses, an awareness, understanding and application of this structured approach to workplace stressors may be beneficial in several ways. Being aware of the potential of the process and the part played by one's beliefs, expectations and assumptions which relate to their workplace may increase the repertoire of coping skills and, as stated above, increased coping resources will help, in the secondary appraisal process, to reduce the likelihood of stress. Learning to assess objectively and recognise their own prime sources of stress may also enhance the likelihood of the nurse reducing or eliminating that problem.

In situations such as dealing with dying patients, where nurses' emotional resources are taxed and well-being threatened, the concept of a problem-solving approach may not be so easily recognised as a useful approach to coping. It may be that problem definition and formulation and the generation of alternatives (as described by Nezu et al., 1989) may be more difficult to accomplish when confronting stressors which place such heavy demands on emotional resources.

However, two examples of the efficacy of this approach stand out in this study. The nursing unit (INT 5 - see page 101 ) which holds short staff meetings at the end of every shift where there has been a traumatic incident has recognised the potential for negative effect inherent in those situations and has learned to take the appropriate steps to alleviate negative outcome. The staff in this unit take immediate steps to discuss and resolve issues and correct problems in the attempt to reduce the possibility of future problems. Further, they recognise the usefulness of the technique in the creation and maintenance of the boundary between home and work. Similarly, the hospice nurse (INT 25 - see page 102), who has recognised the potential for negative effects from long term palliative nursing, has generated a range of strategies for reducing the burden of stress and negative effect which she carries. She has carefully considered the limitations which she must place on giving of herself so that she does not 'burn out' and she has learned how she can ensure that the patient's needs are met at the same time. These are examples of skillful problem-solving coping applied to emotional stressors and more nurses should be taught how to recognise and apply such skills.

This study confirms the recommendation by Tyler and Cushway (1992) that organisational support for stress management programmes which teach coping skills may be a worthwhile investment, particularly with nurses whose basic training ended some years ago. In a recent conference paper, Gray (1997) reported that a range of health-care providers in a head injury unit suffered from many effects of their work which were broadly similar to those reported in this study, especially by general and palliative care nurses. In response to that research, the relevant National Health Service Trust has initiated co-counselling training and peer support groups for the benefit of their staff. Success with such initiatives may encourage other organisations to take such steps.

Some implications also follow from the nurses' accounts of the elements of the experience of patient death which are likely to result in an appraisal of stress. While policy makers must, undoubtedly, put the needs of patients foremost, in a modern enlightened society the effects of policy on the caring professions should also be borne in mind. In this study, however, the data suggests that the needs of patient and nurse converge insofar as some policies may result in detrimental effects for both. For example, some psychiatric nurses felt stressed and anxious about the quality of the care given to patients who, for policy reasons, were discharged after a short hospital stay, only to be returned after a few days

because their condition had deteriorated. A policy which resulted in more available beds and did not demand such fast turnover of patients might provide a better service to the patient accompanied by less stress for the nurse.

Likewise, it appears that recent changes in policy and practice mean that dying patients are kept at home longer, arriving at hospice when they are in the final stages of life and hospice beds are refilled very soon after a patient dies. For the hospice nurses, this meant that they were denied the opportunity to prepare patient and family, control pain and other symptoms and deliver 'the good death' (factors which nurses say create stress). Further, when one death follows very quickly after another and beds are very quickly emptied and refilled, the nurse suffers from a lack of time for grieving, lack of closure, and a sense that she is involved in 'production-line nursing'. If realism in the provision of care requires that these kinds of policy remain, then greater consideration of nurses' needs for support might help to reduce adverse effects for the nurse.

#### 8.3.1.ii - Education and Training

The findings of this study concur with Kelsey (1992), in that nurses perceive their education and training to have been inadequate. Particularly in terms of the work of caring for dying patients and their families, the data from this study provide clear evidence that nurses believe that basic training programmes could be improved in some respects. In particular, they expressed the view that nursing education should include greater and more open discussion of death and dying issues which allowed the nurse to confront his/her own feelings.

Basic training may have changed considerably since the majority of the nurses in this sample went through their training, and since the survey conducted by Field and Kitson (1986). In their study, Field and Kitson reported a mean number of 13.5 hours taught on death and dying in a nursing degree, which was considerably more than the mean in SRN/RGN or SEN/EN courses. However, information from a local school of nursing indicated that a full 20 hours are allotted during the core foundation section of the Project 2000 course and as much as 45 hours in some of the branch sections of the course. Content focuses on the skills required to provide care for patients and families and, crucially, includes exploration of personal attitudes to death and dying. While a sample of

one nursing school cannot provide the national or even regional picture, this information suggests that there may be an increased recognition of the needs of nurses and an attempt to address those needs. It will be impossible to assess fully the adequacy or the benefits of these educational changes until more of these students have been in the workplace for some period of time. However, the refinement and use of a reliable measure of perceived competence to deal with death and dying issues would provide some assistance in assessing the efficacy of death education. See below (8.3.3) for discussion of methodological implications related to measures used in this study.

Although it appears that nurse educators may have taken account of nurses' need for greater study of death and dying issues during the basic training, this does not alleviate the problem which exists among nurses who trained some time ago. There are post-basic training courses in death, dying and bereavement, perhaps the best known of which is the ENB 931. However, as reported above, it seems that for some nurses, gaining access to these courses is often difficult or comes later in their career than they would wish. Greater investment in training at both basic training and post-basic stages of the nursing career may pay real dividends in terms of improved well-being for nurses.

Also in line with Kelsey (1992), there is evidence in this study that shared experience is a vital part of learning how to deal with death and dying, and is particularly important for young nurses. This may be an important aspect of training for those nurses who are new to ward experience. Coupled with the importance of social support in coping with stress, this emphasises the need for teams, mentors and discussion groups so that nurses are not left in isolation and are given the necessary opportunities for ongoing learning. This is particularly important for managers of nurses who work in the community settings where team or group structures may not be so available as in hospital settings.

The results of this research suggest that, with clinical experience of patient death, there may be an increase in death-related fears but that even greater clinical experience/training may play a role in the eventual decrease in fear of death. The data also suggest that the nature of the experience of patient death may also influence how the experience affects personal fears or attitudes. In the interests of continued learning, and in the interests of helping nurses to cope with their personal fears, nurses at all stages of their careers should be given the opportunity and encouraged to share and discuss death-related experiences

and aspects of their work. Nurses in this study recommended that these discussions should not be restricted to practical nursing issues but should include an opportunity for the nurse, as an individual, to discuss his/her own fears and the effect of the work on those fears and vice versa. Many argued that it is not sufficient to address personal attitudes during basic training only. Throughout a nursing career, life and work experiences may cause changes in attitudes and fears which need to be addressed if a nurse is to do this demanding work with increased confidence and without serious negative effects.

Notwithstanding the above, it is fair to ask whether an individual can ever be trained or educated to cope with death and dying, to the extent that there is no stress associated with the experience. In theoretical terms, according to Lazarus and Folkman (1984), this would require that nurses would feel so able to deal with death and dying that they could appraise the situation as being either irrelevant (an unlikely and probably undesirable situation) or as a challenge rather than threat. It is evident from the data that some nurses, in some circumstances, have found the latter appraisal possible. The aim must be to facilitate greater confidence and perceived resources and competence to deal with this work.

### 8.3.1.iii - The Culture of Care

Several issues relating to the nursing ethos and culture of care have arisen from the data. These pertain to the difference between theory and practice, the attitudes of doctors towards nurses, and the care of dying patients in terms of the nurses' expectations and attitudes to the elderly and the dying, especially on general wards.

In line with previous research (Field, 1986; Melia, 1987), the evidence in this study indicates that, in some instances and particularly in respect of holistic care, there still exists a wide gap between nursing theory and training and nursing practice. In the view of many nurses from all three groups in this sample, the gap is widening with the changes in health service provision which, in the nurses' perceptions, has meant that they often have too little time to nurse in the holistic way. This causes problems for the nurse in several ways, clear evidence of which is found in Chapter Four and Chapter Six. First, there is discomfiture from being unable to perform duties in the way which has been learned as the correct and professional way. There was clear evidence of this in the ratings of sources of stress (Chapter Four) which placed the inability to meet patients' needs as one of the most

important stressors, as well as in the qualitative data. Secondly, there is a loss in job satisfaction arising from the perception that the job is not being done as well as it could be done. Thirdly, nurses, who are the front-line contact, often bear the brunt of patients' complaints when the patient feels that service has fallen short of expectation, and if the nurse perceives that service is less than ideal for reasons beyond his/her own control, s/he may feel abused by both the patient and the system within which s/he works.

In the case of caring for the dying and the bereaved, feeling that one has not been allowed to give the ideal care to a patient in the final hours of life adds immeasurably to the stress associated with the experience. When the reasons for not achieving professional aims and standards are beyond the nurse's control, this adds to the negative consequences, for the nurse, of doing this emotional work. One of the major sources of stress in the experience of patient death has been said by nurses in this study to be insufficient time and opportunity to prepare patients and families adequately for the impending death so that in the end, the nurse can facilitate the 'good death'. It is clear that this need is well recognised throughout this sample, and especially in the hospice and palliative care groups. It is also clear that having this time and opportunity provides benefits for patient and family as well as for the nurse. Whether or how policy might be changed to insure that these benefits may be accrued is for others to decide.

Throughout this study there were several instances of nurses reporting stress related to conflict with members of other professions, and especially with doctors. Generally, these problems arose out of disagreements about the nature of treatment and pain-control. The differences of opinion were perceived to arise because the doctors either would not consult with nurses whose expertise in pain-control was greater than that of the doctor, or would not accept the opinions of those nurses. It appears that some doctors are still reluctant to accept and value nurses' expertise, particularly in the area of palliative care. This results in nurses feeling undervalued and unsupported but their accounts clearly focused on the repercussions for patients. Since doctors still largely (though not always) have the last word on treatments, some nurses felt their patients had not had appropriate care.

Although Fisher (1991) and others have written about nurses' unrealistic expectations in terms of caring for the dying, this approach seems to be too simplistic. Nurses in this study do, on the basis of their training and experience, appear to expect that a patient

should be able to die free of pain. Alexander and Ritchie (1990) view this as an impossible aim and report that nurses feel helplessness and impotence when their patients die in suffering. In this study it was clear that these emotions were often accompanied by anger. Where a pain-free death is not achieved, many nurses see this as the result of a failure to use appropriate methods of care and medication, rather than an unrealistic goal. Among the nurses interviewed in this study, there was a sound understanding and acceptance of the inevitability of death and the inherent sadness and loss. There was also an awareness of the unrealistic nature of some of the patients' and families' wishes which sometimes caused the nurse to feel they were 'letting people down' when they were unable to fulfill those wishes. Nevertheless, nurses appeared to be firm in their perception that patients who died in pain were indeed being let down.

It is worth considering the perception, which appears to be held by nurses in this study, that in general nursing wards the focus of care shifts away from patients who are dying. Several of the nurses in this sample held very strong feelings that these patients were not given the kind of care and attention which the nurse perceived as desirable. It is important to determine whether this perception is held by other medical staff and/or is a reality. This requires further study but, if it is the case, then clearly there must be negative effects for the patients and their families as well as for the nurses.

The primary goal must be to meet the patients' needs but it appears that this goal may accord with the aim to achieve better management of patient death (with less stress and negative outcome for the nurse). In hospital units, data from this study suggests that achieving these goals would require some changes in the attitudes and ethos of care among all medical staff and management. In part, this attitude may change through increased training with, potentially, a subsequently increased confidence among nurses in their ability to deal with death and dying. It may also change through confrontation and more open discussion of death-related issues among staff groups, requested and recommended by nurses in this study. The changed ethos would need to be shared by doctors and management if it was to be put into practice, for there are implications for staffing and funding which may not be easily accommodated by already over-stretched budgets.

### 8.3.2 - Theoretical Implications

#### 8.3.2.i - The Transactional Perspective of Stress in this Study

The transactional perspective of stress, as proposed by Lazarus and Folkman (1984), has provided a useful framework for this investigation of stress. In dealing with the nursing role, the environmental factors are important as has been shown by the differences in the responses of nurses from different clinical areas to questions about stress. Lazarus and Folkman emphasised the individual nature of the stress process. The role of personal factors in the determination of stress is highlighted in the qualitative data in this report where there are several instances where the individual has contradicted the group response. However, within groups, especially where the individuals are focused on the same commitments and goals, there appears to be much similarity of response to some stressors. For example, in Chapter Four, it can be seen that approximately 50 percent of the sample attributed high importance to some of the potential stressors. The complexity of this model is obvious and remains grounds for criticism. While the complexity allows for many factors to be involved in the causation of a stress appraisal, the same complexity makes it very difficult to apply or investigate all of the facets of the model within one sample or one investigation.

In the study of patient death as a stressor, the Lazarus and Folkman (1984) transactional perspective appears to have been appropriate insofar as the nurses perceive patient death as being stressful and as a stressor. In conversation, the nurses use those terms to refer to the experience, in the same way as they refer to a lack of resources or work overload. However, the apparent perception that the stress associated with patient death is different from that caused by other stressors suggests that patient death may be a unique stressor. Used on its own, this model of stress may be inadequate to study the experience of nursing the dying and patient death.

The integrated findings, discussed above in 8.2, have highlighted the complexity of the nursing experience and demonstrate the layers of influence which interact and impact on the nurses. For example, in the general nursing group, findings include perceived lack of competence, lack of support, organisational constraints which affect their ability to deliver holistic care, perceived inability to deliver the good death and higher reported levels of fear



of death. In the palliative care group, nurses appear to feel more confident about their skills, their support systems, their resources and their ability to achieve good death for their patients and they report lower levels of fear of death. It remains somewhat puzzling that there are no significant differences in levels of reported well-being. This may suggest some insensitivity in the GHQ-12 instrument measuring psychological well-being. Because questions in this scale are worded to ask about change over recent weeks, this scale may not be appropriate as a measure of level of well-being, and may only signify recent changes in well-being. Hence, results may signify that neither group has experienced significant change over recent weeks but do not necessarily indicate whether groups are experiencing high or low levels of stress at the time of completing the scale. This suggests that future research to measure levels of psychological well-being requires the use of a different instrument.

The importance which nurses have given to providing the 'good death' seems to indicate that this is an area where further research may be beneficial. These data indicate that there are several elements involved in nurses' perceptions of a 'good death' and it is possible that these elements should be investigated in terms of the incidence of 'good' or 'bad' deaths and their effect on nurses. It may also be, as Lazarus (1990) has suggested, that the research should be more focused on the emotional responses or the effects of the stressful encounter. Especially in nursing where stressful situations may be unavoidable, focusing on the impact of those situations may have the added benefit of encouraging organisations to make better provision for support for nurses.

It is also suggested that, in order to understand more about patient death as a stressor, it may be fruitful to consider the different perspectives on death. For example, cultural, religious or philosophical attitudes towards death may influence how a nurse copes with the event of patient death. The Lazarus and Folkman (1984) model does account for some of these attitudes in terms of commitments and beliefs. However, when dealing with death and fears related to death, we may be dealing with many unconscious factors (Lonetto, 1986) which may not easily be accounted for in such a model of stress.

Kelly's personal construct theory (1955) and the repertory grid technique have been used to study death attitudes (Tomer, 1994). In this technique, an individual formulates constructs based on the ways in which parts of their experience fit together, eventually

developing a hierarchical pattern of importance of the constructs which reveal a belief system. Some of these constructs may be changed without serious changes to others but some major constructs are vital to an individual's outlook on life and if they are changed or threatened, anxiety is the likely result. Previous work using this technique with death attitudes has primarily investigated how people react to considering death as a part of their own personal constructs (Neimeyer and Moore, 1989). It is possible this technique might fruitfully be used to explore in greater detail the meaning and importance of patient death in nurses' own terms. This may reveal information about nurses' fears about death and dying and the relative importance of the stress associated with patient death. A study incorporating psychodynamic perspectives on death may also inform future research directions, as the basis of some aspects of fear of death may have childhood roots and may be difficult to verbalise.

Much of the work in this study was exploratory in nature, attempting to advance the understanding of the nursing experience of working with dying patients. The instrument of measure for fear of death, while previously used in this country, has only limited previous use, and has not formerly been used with nurses. The scales from the United States for measuring coping with death/death self-efficacy are also very new and in need of more research for validation. The accumulated loss phenomenon scale has, as far as can be determined, only been used once in the United States with a much smaller sample and only with hospice nurses. Therefore, the data from these scales requires further replication before the results can safely be generalised. However, this study has provided considerable advance on this work and leads to some theoretical questions which will be helpful in setting directions for future research (discussed in more detail below). The theoretical implications of these findings are primarily focused on two areas: fear of death and accumulated loss and are discussed below.

### 8.3.2.ii- Fear of Death

Acknowledging the need for much more research and for caution in generalising these findings, there are three important theoretical implications or questions which have arisen in respect of fear of death. These relate to the lack of normal distribution in reported scores, to the direction of increase/decrease in fear which may result from clinical

experience of death and dying and to the relationship between frequency of thought about dying and fear associated with dying.

Only through more research among wider and more diverse populations can the issue of distribution of scores be clarified and understood. If this feature is present in most samples, then there are, as in this study, limitations on the kinds of statistical testing which may be used to draw conclusions from the data. It is rare in a published research paper to see an acknowledgement that data did not fit the criteria for normal distribution. However, when dealing with a subject as emotive as death and dying, it is possible that this skewed data may be 'the norm'.

The second theoretical question arises from the findings that general nurses report higher levels of fear of death than the general population and palliative care nurses report lower levels. As previously stated, this gives support to the idea that clinical experience in nursing affects fear of death. The direction of effect seems unclear, although one may conclude that some clinical experience and the nature of that experience are related to an increase in fear and greater clinical experience, perhaps including 'good death' experience, is related either to a decrease or levelling off in fear. However, there remains a question about the possibility of selective volunteering for palliative care by those nurses who are already less fearful. Although quantitative instruments allow useful comparative measurement of attitudes, it is suggested that a more effective way in which to approach this issue may be through the use of longitudinal case-studies of individuals.

Finally, the data in this study clearly showed differences in response to questions about frequency of thought associated with death and dying and the levels of fear associated with those thoughts. These differences are clear from two aspects of the data, previously reported in Chapter Five. Correlations between frequency of patient death experienced and frequency of thoughts about death are, as expected, positive. However, correlations between frequency of patient death experienced and levels of reported fear are negative. Further, palliative nurses report significantly higher frequency of thought about death and dying, yet do not report higher levels of fear. These findings indicate the need for further research into the relationship between levels of fear and frequency of thought about death. The assumption underlying the fear of death questionnaire seems to be that thinking about death equates with fear but the data suggest that this may be not be a safe assumption. As

previously mentioned, qualitative research may provide insight into how individuals may think about death and dying. The concept of psychologically healthy individuals being able to think about death without fear is worth exploring.

Although there has been a considerable amount of research into death attitudes in the United States, as was stated in Chapter One, there is a need to continue research in the United Kingdom. Arguably, an important focus of the research should be those factors in fear of death, which may act as moderators. Examples of such potential moderators would be ethnic value systems, recent bereavements, and recent multiple deaths which have gained public attention (such as the events at Hungerford - a multiple shooting by a deranged gunman, or Lockerbie - a plane crash which resulted in many deaths). A greater understanding of the moderators of fear of death may assist in practical ways when dealing with victims' families and survivors of such traumatic events, as well as informing health-care professionals in the broader range of caring situations.

### 8.3.2.iii - Accumulated Loss Phenomenon

In theoretical terms, it would not be unreasonable to expect that some nurses, faced with a large number of patient deaths, would suffer from an accumulation of adverse effects. Adams et al. (1991) contended that they found evidence to support the existence of a unique phenomenon of accumulated loss. However, while there is evidence that some nurses may suffer from the accumulated effects of working with the terminally ill and experiencing the death of many patients, there is little support, in these results, for the concept of the unique phenomenon of accumulated loss as described by Adams et al. (1991). As discussed above, there are apparent deficiencies in the instrument used in this study to measure accumulated loss and it is acknowledged that this study does not definitively deny the existence of a set of experiences which are unique to some nurses who experience many patient deaths. However, it is concluded that the symptoms addressed by Adams et. al. are not unique among hospice carers and might be explained by the concept of burnout (Maslach and Jackson, 1981) resulting from the accumulative effects of working with many dying patients. Further research using longitudinal qualitative approaches such as case-studies, diaries and interviews is recommended.

### 8.3.3 - Methodological Evaluation

As with any research project, consideration of the completed work inevitably informs about the ways in which the project might have been improved and highlights methodological changes which would improve further research. Throughout the study, there are acknowledgements of problems relating to particular methodologies, the measurement of subjective ideas such as stress, and the problems associated with sampling and distribution of questionnaires in this study. These and other issues may affect the findings in ways which are difficult to assess and therefore demand a cautious approach to generalisation of findings until further research can be carried out.

In this research, three of the quantitative measures used were very new and one aim of the work was to produce more information about the nature and usefulness of the instruments. In particular, this related to the Coping with Death Scale (Bugen, 1980-1981), the Death Self-Efficacy Scale (Robbins, 1992) and the measure used by Adams et al.(1991) on the basis of which they proposed the unique phenomenon of Accumulated Loss. This section will discuss the implications of the findings in respect of these three scales, as well as methodological issues related to other aspects of the study.

#### 8.3.3.i - Coping With Death (Bugen, 1980-81) and Death Self-Efficacy (Robbins, 1992)

As discussed in Chapter Six, the reliability statistics show that each of these two scales demonstrated good internal consistency but exploratory factor analyses suggested considerable overlap between the two scales. While Robbins' work has advanced on Bugen's work by broadening the range of issues measured, further work is required, as discussed in Chapter Six, if there is a wish to develop a single reliable and efficient instrument for use among professional health-care workers, to measure perceived competency to deal with death-related issues.. This work should incorporate the use of larger samples and samples from other populations of professional health-care workers such as nurses from other clinical areas or doctors. Careful attention must also be given to the item content of the instrument, considering whether the scale is meant to assess perceived competency/working skills or coping abilities or a combination of both.

This is an area of research where some focused qualitative research into attitudes to death may assist in the refinement of item content. For example, what is perceived, by a respondent, to be the meaning of 'coping with the death of a parent' or 'handling the illness of a child' or 'allowing a patient to communicate fully' and especially 'understand bereavement and grief' (from the accumulated loss scale, Appendix Iii). Terms such as 'handling' and 'understanding' may be defined in many different ways and, at best, may be relative terms. It may be that most individuals have a broadly similar understanding of such terms but there is an obvious need for further refinement of these items.

### 8.3.3.ii - Accumulated Loss Phenomenon (Adams et al., 1991)

As discussed in Chapter Seven, data from this scale has provided little support for the proposed phenomenon of accumulated loss. If a quantitative instrument is to be used in further investigation of this concept, there is much more work to be done. There is a need for a clearer focus within the item content as this scale appears to be measuring a large number of factors. Further, it would appear that there is considerable similarity between some of the areas in this scale and the factors measured by the burnout instrument. However, as indicated by the qualitative data, there is evidence of accumulative effects on nurses of working with many dying patients and the area is worthy of much more research. This suggests that the concept of accumulated loss is one which would be more effectively investigated through qualitative means. In-depth interviews, diaries or log-books and perhaps even case-studies over a period of time, could provide a richer source of data. If it could be established that there is sufficient evidence of a phenomenon which appears to differ significantly from burnout, the qualitative data would then be useful in developing a more focused quantitative instrument.

### 8.3.3.iii - Fear of Death (Howells et al., 1986)

There are, as discussed in Chapter Five, two methodological issues relating to the fear of death instrument used in this study. These pertain to the meaning which respondents may give to some of the questions and the use of a combination of levels of intensity and frequencies of thoughts about death. While it has been said, in Chapter One, that this scale presents a straightforward approach to fear of death and an instrument with good face

validity, from data reported and discussed in Chapter Five, it would appear that there is still room for further investigation and improvement in terms of item content.

As with the measurement of stress, it is acknowledged that a concept such as fear of death is difficult to measure with accuracy. This emphasises the need to improve face validity so that the meaning inherent in each question should be clearly understood in a way which is very similar for all respondents. Specifically, this relates to the question about fear associated with being dead, and to the questions about frequency of thought about death. It may be better to ask about the frequency of 'feeling frightened about dying' or 'thinking unpleasant thoughts about dying' to allow for the possibility of being able to think about one's own death without fear.

Again, this is an area which may benefit from a qualitative approach to gathering the detailed information about how individuals conceptualise fears related to death and dying and about the relationship between frequency of thought and intensity of fear, which is required to refine this instrument.

This study has included a survey of fear of death in a general population sample to allow comparisons with the nursing samples. Any further research into fear of death would benefit from greater use of general population sampling either for quantitative or qualitative investigation. The return rates in this study (23 percent on the general population survey) give some indication of the difficulty in gathering adequate samples for studies of fear of death. However, it is essential that a much wider sample is surveyed before statistics can be used safely as baselines against which to measure more specific populations.

#### 8.3.3.iv - General Methodological Issues in This Study

The use of both qualitative and quantitative methods in this research was discussed in Chapter Two. Further, throughout the thesis, it has been acknowledged that there has been considerable convergence and some divergence in the data gathered from the two methods. It is worth emphasising that the benefits of using the two methods is apparent from this work. The interview and diary data has provided clarification of quantitative results (for example, on sources of stress for different groups of nurses and on respondent

interpretation of some questions used on quantitative instruments) and richness of data (about the elements of the experience of patient death which are most likely to result in an appraisal of stress and about the effects of the work on nurses).

Limitations of the use of anonymous diaries were also made apparent by their use in this study. Because the authors of diaries were promised anonymity, once posted by the researcher, the diaries could not be traced to individual participants. This meant that there was no effective way of encouraging an individual who had not returned their completed diary. Further, in an attempt to encourage returns and to keep the burden of writing to a minimum for the nurse, the diary questions were, of necessity, fewer in number and focused on stressful events, especially patient death, and their effects. However, the rich and rewarding data from the few diaries in this study gave clear indication that diaries are a useful tool in the qualitative area of research and, with careful design and focus, can be a highly effective way of collecting data.

As previously mentioned, this study has also raised the suggestion that qualitative methods such as interviews, focus groups or long-term case studies, may be more effective in future research in gathering data on such issues as coping, effects of nurses' stress on patients, changing patterns of fear of death and individual understanding of concepts. This may be especially true in the study of death and dying. Such qualitative methods allow individuals to gain a sense of trust in the researcher which may increase their willingness to disclose about emotionally charged issues. The time involved in interviews and case-studies also allows participants the time to reflect on difficult issues and potentially to verbalise ideas or attitudes which may have been unconscious. Although it may be difficult for a non-nurse researcher to obtain consent to observe nurses in their work, this might provide a detailed account of the reality of some aspects of nurses' coping and nurses' reactions to their experiences of patient death which could then be compared with self-report accounts. As discussed in 8.3.2.iii, patient death as a stressor might usefully be explored in interviews using the personal construct theory and repertory grid (Kelly, 1955) or from a psychodynamic perspective, possibly using pictures or stories to explore meanings of death-related experiences. In addition, further research might improve on this study by incorporating feedback sessions with interviewees to discuss and agree themes and interpretations which the researcher draws from the data.



In this project, the questionnaire package sent to nurses was large and time consuming to complete. Some nurses also appeared to find the subject matter of the questions unpalatable. Several questionnaires were returned, uncompleted, with comments suggesting that the survey was “too depressing”, “too boring” and “yet more paperwork”. This may account, at least in part, for the return rate in the nursing sample being just under 30 percent. A larger sample size may have produced data with a more normal distribution pattern which would have allowed the use of parametric statistical analyses. However, achieving a higher rate of volunteer participation, in the circumstances where the researcher is granted only limited direct access to the nurses, as previously described, has proved difficult.

The time frame within which the two phases of Study 1 were carried out is also likely to have affected the number of participants in the second phase (interviews and diaries). During Phase 1, 79 respondents volunteered to participate in Phase 2. However, by the beginning of Phase 2, the numbers of those who actually agreed to interviews or who actually completed diaries in lieu of interviews had dropped significantly. It is acknowledged that the time lag between Phases 1 and 2 was too long and allowed a loss of momentum to occur.

Although the samples used in the project were large (308 nurses, 450 of the general population), they were, inevitably, volunteer samples. Previous sections of the report have mentioned the potential for inherent bias. However, in the case of the nursing sample, this particular sample does not appear to be substantially different from other samples in terms of psychological well-being, and is larger than samples found in many previous studies.

The skewed nature of much of the data from this study prevents the use of multivariate analysis which would help to clarify some of the relationships among the variables. Volunteer samples undoubtedly play a role in the skewed nature of the data, particularly when the subject matter is so emotive. Particularly with respect to death and dying surveys, it is possible that respondents tend to be only those who hold strong feelings about death and dying, either being very fearful or very confident about death and dying at the time of survey. However, it may be that death and dying are such emotive issues that most people will have strong feelings in one direction or the other. In that case, it would be very difficult to find responses which would fill the central portions of the scoring

range. The issue of normality of data in death attitudes research requires further investigation, as do several other issues which are discussed in the following section.

#### 8.3.4 - Future Research

The necessity for further research has been acknowledged throughout the above chapters. Some specific areas of need have been acknowledged and some ideas for direction have been expressed. The work has generated other ideas for investigation which may lead to a better understanding of the nurses' experience and/or improvement in outcome of the nurses' interaction with his/her very demanding environment.

In line with the above recommendation that problem-solving approaches could helpfully be used more often by nurses, even when dealing with emotional stressors, it would be beneficial to study the effects of problem-solving training on nurses' responses to emotional stressors. This would require a longitudinal approach, assessing change in response to stressors and change in perceptions of coping ability before and after training. The use of problem-solving in dealing with mental health problems is largely based on the theory that there are specific skills, both cognitive and behavioural which can influence emotional reactions. There is already a range of different methods, including self-report and observational, which could be used to measure competence in this regard (Nezu et al., 1989). Some of these may need to be adapted for use in nursing settings.

Further to the above comments on the need for further research into death attitudes, there is also a need to investigate differences in death attitudes between other medical workers and the general population. Professionals need to recognise differences in attitudes which may exist in their patients and the related effects on adherence to treatments, grieving and bereavement reactions.

A more complete understanding of the reality of nursing dying patients in 'general' settings may alleviate some nurses' concerns about quality of care. Research should address perceptions, of all of the medical and nursing staff, of the adequacy and appropriateness of nursing practice in respect of dying patients and if possible, bereaved families' perceptions of quality of care. While interviews with individuals would be necessary, focus group discussions may also shed light on where and why differences of opinion may exist

between different sections of the staff. It is also suggested that observational studies of nursing units might provide a more accurate account of nursing practice.

This project has investigated nurses from only three clinical areas and wider sampling is necessary if findings are to be generalised with confidence. However, the study has highlighted a need to help many nurses feel more able to cope with death and dying issues. It is suggested that further research is required to ascertain how this might be best achieved. Formal training may provide part of the answer but open discussion, focus groups and sharing of experience, may also be effective. Further, the changes in nurse education, which have been discussed above, to include a greater emphasis on death and dying issues need to be followed by research to see whether Project 2000 nurses demonstrate greater perceived ability to cope with death and dying and lower levels of fear of death.

Ideally, research should be longitudinal, beginning with student nurses, who have not yet studied their core foundation module which covers death attitudes, and following the students to see the effect of the different sections of their training and ward experience, especially their first experience of patient death. Students might be followed through several experiences of patient death, either 'good' or 'bad', to investigate the impact of those deaths on well-being, death self-efficacy and fear of death. The establishment, monitoring and evaluation, on an experimental basis, of a provision of support, counselling and supervision through early years of the nursing career would provide a strong test of the value of such a provision and might provide guidance for realistic and practical support systems for nurses.

Feedback from some nurses in this study has indicated that being interviewed and keeping the ten-day diaries are actually beneficial activities for the nurse. Some nurses who were interviewed felt that it helped them to talk to someone who was interested but independent. The interview provided an opportunity to say things, in confidence, which they felt unable to share with family and which they felt their colleagues did not want to hear. These findings suggest that these nurses had a need for some kind of counselling facility and that an evaluation of counselling services available to nurses would be useful. Comments from nurses also indicated that both interviews and diaries helped the nurse to reach a clearer picture of the sources of his/her stress. Diaries had sometimes been used in

much the same way as reflective journals which some nurses already use. It would be useful to investigate the efficacy of these and other instruments when used as stress-relief techniques.

The evidence in this study leads, undoubtedly, to the conclusion that research into death attitudes holds some methodological challenges. The subjectivity of understanding of such concepts as fear of death makes the measurement of these concepts difficult. So too does our lack of understanding about factors which may, over time, influence personal fears. The impact on fears of life experience, personal loss, and media coverage of traumatic incidents or disasters is not yet understood and poses investigative challenges. Nevertheless, methodological challenges, however difficult, should not deter the attempt to improve our understanding of the psychology of death and dying, this most inevitable part of human existence.

To conclude, this study has advanced the investigation of fear of death in nurses who are depended upon by the remainder of society to care for and support the dying and their families. That nurses report levels of fear of death which differ significantly from those reported by a general population sample is a finding which deserves attention. These same nurses, especially those in general nursing units, appear to lack confidence in their training for and ability to cope with their work and with a range of death and dying issues and often report that they work in short-staffed, poorly resourced situations where they feel unsupported by their leaders and have some difficulty in accessing the social support which they believe is the most effective coping resource. The great importance attributed by nurses to achieving a kind of care which leads to a 'good death' is evident in this study. It is also evident that nurses lack confidence in their ability to deliver this good death, whether through their own lack of competence or/and because the system thwarts their efforts. In response to these difficulties, nurses perceive an increase in stress associated with patient death when they are unable to deliver this good death. These findings deserve even more urgent attention. If psychological stress is, as Lazarus and Folkman (1984) described, a relationship between person and environment which is appraised by the person to tax or exceed his/her resources and endanger his or her well-being, then the situation for these nurses is filled with potential for high levels of psychological stress. It is remarkable that, while nurses report their work to be stressful, many also report high levels of job satisfaction.

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## APPENDICES

### APPENDIX 1 a

Sample of letters sent to Local Health Authority, and various nursing managers to gain volunteers for the project.

Sylvia McNeely  
Department of Psychology  
Nene College  
Moulton Park  
NORTHAMPTON  
NN2 7AL

Date

Dear.....

I am a post-graduate research student in the Psychology Department at Nene College, working under the supervision of .....

The research project is to study occupational stress and coping strategies within the field of nursing. My particular interest is in how nurses cope with the death of their patients. Subjects (1200) will be evenly drawn from three areas, ie psychiatric, general and palliative care.

The study will be a comparative study aiming to find evidence of particular coping strategies which might be used by nurses to reduce the harmful stress of this aspect of their work.

Methodology will be the use of questionnaires requiring about 30 minutes to complete, and semi-structured interviews with a reduced number of subjects.

I would be very grateful if you could advise me about how I might recruit volunteer subjects from the nursing population in this area. Any comments you care to make regarding the study, sources of relevant information, etc, would be most welcome. For example, it would be helpful if you could direct me towards those individuals who teach aspects of nursing which would be relevant to this study.

Thank you for your time and consideration and for any assistance which you may be able to offer me in this matter.

Yours sincerely



**APPENDIX 1 b**

(Sample letter)

Date

To

Dear

I am a postgraduate research student in the Psychology Department at Nene College, under the guidance of .....

The project on which I am working is a study of stress among nurses from three specialisms (palliative, general and psychiatric nursing). All professionally qualified nurses are eligible to participate and it is hoped that there will be approximately 400 nurses from each area.

The study will involve a comprehensive study of stress and the use and effectiveness of coping strategies. In addition, it will look at how nurses think about death and how this affects their well-being and their ability to cope with the stress of their work.

In the first phase of the work, self-report questionnaires will be used, followed by personal interviews with a reduced number of volunteers. It is anticipated that some nurses will only wish to participate in the questionnaire while others will be interested in both phases and all nurses will have the opportunity to volunteer for interview.

All information will be treated anonymously and will be published as part of a doctoral thesis. Results and information from the research may be published in the relevant journals.

I would be most grateful if you and your staff would consider participation in this project. I recognise the pressures of work under which your staff operates and will take as little of their time as possible.

It would be very helpful if you could please advise me of your decision fairly soon, and if it is a positive one, the approximate numbers of nurses involved. If you require further information or would like to speak to me by telephone, I may be reached on ..... I would also be happy to come to your office to discuss any aspect of the work with you.

Thank you for your time and consideration in this matter. I look forward to hearing from you in the near future.

Yours sincerely

## **APPENDIX II a - Introduction/Instructions for Questionnaire - Study 1 - Phase 1**

Thank you for agreeing to participate in this research project. Research into stress among carers (rather than the patients) is a relatively new area of study. I am grateful for the opportunity to focus on this important topic for the next three years. This project is the basis of a doctoral thesis (Psychology) and follows an undergraduate study carried out in 1992/93.

The study is intended to be:

- a comparative and comprehensive study of stress among nurses,
- a study of how nurses think about death and how it affects their well-being and their ability to cope with the stress of their work, and
- an assessment of coping strategies and their effectiveness.

As you work your way through the battery of questionnaires, I hope that you will not see this as 'just another addition to the already heavy burden'. I hope that you will complete and return the questionnaire and join me in the search for information which can be used BY NURSES FOR NURSES to ease some of the effects of carrying that burden.

There are three sections to the questionnaire. PLEASE TRY TO COMPLETE ALL THREE SECTIONS. However, if you feel that you cannot do so, please return the SECTIONS THAT YOU HAVE COMPLETED so that at least that information may be used.

All information received in this study will be treated anonymously. Information about the study and the findings from the research will be published as part of a doctoral thesis.

Enclosed in this pack are:

### **Questionnaires**

LARGE stamped, addressed envelope for return

Reply sheet for interview volunteers

SMALL stamped, addressed envelope for return

In order to preserve your anonymity in regard to the questionnaire portion of the study, please return ONLY the questionnaire in the LARGE envelope.

If you are prepared to be interviewed at a later date (probably late 1994 or early 1995), please complete the enclosed form and return it separately in the SMALL envelope.

QUERIES TO: MRS S McNEELY, RESEARCH STUDENT, PSYCHOLOGY DEPARTMENT, NENE COLLEGE, MOULTON PARK, NORTHAMPTON, NN2 7AL

THANK YOU FOR GIVING OF YOUR VALUABLE TIME TO PARTICIPATE IN  
THIS RESEARCH PROJECT. YOUR INTEREST AND ASSISTANCE ARE  
GREATLY APPRECIATED.

# APPENDIX II b - GENERAL QUESTIONNAIRE - 2.2.2.iii - 1

- 1 What is your age?
  - 1 under 30 \_\_\_\_\_
  - 2 31 - 40 \_\_\_\_\_
  - 3 41 - 50 \_\_\_\_\_
  - 4 51 - 65 \_\_\_\_\_
  
- 2 Are you
  - 1 male \_\_\_\_\_
  - 2 female \_\_\_\_\_
  
- 3 Do you live
  - 1 alone \_\_\_\_\_
  - 2 within a family group \_\_\_\_\_
  - 3 with a partner or spouse \_\_\_\_\_
  - 4 other (please specify) \_\_\_\_\_
  
- 4 Are you:
  - 1 Macmillan or Marie Curie Nurse \_\_\_\_\_
  - 2 not 1 but working primarily in palliative care \_\_\_\_\_
  - 3 working in psychiatric nursing \_\_\_\_\_
  - 4 doing general nursing (NOT in palliative or psychiatric unit) \_\_\_\_\_
  
- 5 Do you work in
  - 1 hospice \_\_\_\_\_
  - 2 hospital \_\_\_\_\_
  - 3 community \_\_\_\_\_
  
- 6 Number of years worked in this unit
  - 1 2 or less \_\_\_\_\_
  - 2 3 - 5 \_\_\_\_\_
  - 3 6 - 10 \_\_\_\_\_
  - 4 more than 10 \_\_\_\_\_
  
- 7 Number of hours worked per week
  - 1 less than 15 \_\_\_\_\_
  - 2 15 - 25 \_\_\_\_\_
  - 3 26 - 40 \_\_\_\_\_
  
- 8 Please give your nursing grade \_\_\_\_\_
  
- 9 Have you had extra training especially for:
  - 1 palliative care \_\_\_\_\_
  - 2 psychiatric nursing \_\_\_\_\_
  - 3 care of the dying patient \_\_\_\_\_
  - 4 bereavement counselling \_\_\_\_\_
  
- 10 Do you feel your training has adequately prepared you for:
  - 1 communicating with and caring for the dying \_\_\_\_\_
  - 2 coping with relatives of the dying \_\_\_\_\_
  - 3 dealing with your own feelings about patient death \_\_\_\_\_ (cont...)



## APPENDIX II c - Sources of Stress Questionnaire - 2.2.2.iii - 2

Please enter the number of the response which best describes how you feel about each of the following aspects of your work: 1 = not stressful, 2 = only occasionally stressful, 3 = somewhat stressful, 4 = quite stressful and 5 = extremely stressful. Stressful is defined as causing you worry, making you feel pressured or anxious.

- |  |       |
|--|-------|
| 1 Inadequate staffing in the unit  | _____ |
| 2 Inadequate understanding/support from senior staff                           | _____ |
| 3 Incompetent/unqualified staff  | _____ |
| 4 Death of my patient  | _____ |
| 5 Caring for critically ill patients   | _____ |
| 6 Dealing with relatives   | _____ |
| 7 Quality of care given in the unit  | _____ |
| 8 Necessity to maintain professional image in the face of emotional situations | _____ |
| 9 Relationships with staff   | _____ |
| 10 Home/work conflicts   | _____ |
| 11 Verbally abusive patients   | _____ |
| 12 Very difficult/violent patients   | _____ |
| 13 Shortage of resources in the unit   | _____ |
| 14 Lack of control over decisions about patient care                           | _____ |
| 15 Bereavement counselling   | _____ |
| 16 Too much work/too little time   | _____ |
| 17 Inability to meet patients' needs   | _____ |
| 18 Lack of opportunity for personal growth/advancement                         | _____ |
| 19 Relationships with dying patients   | _____ |
| 20 Coping with new technology  | _____ |
| 21 Lack of specialised training  | _____ |
| 22 Being asked to do tasks outside my competence                               | _____ |
| 23 Dealing with my emotional involvement with patients                         | _____ |
| 24 The necessity to give of myself continually                                 | _____ |

If there is anything NOT on the above list which you find particularly stressful, please state what that is and how stressful you find it (using 1 to 5 as above)

---

**APPENDIX II d - General Health Questionnaire - 12 (Goldberg, 1972, Goldberg and Williams, 1998) 2.2.2.iii - 3**

The following questions refer to how you have been feeling in the last few weeks. Each question has four statements underneath. Please circle the statement that you feel is most true for you. Thank you.

1 Been able to concentrate on what you are doing?

Better than usual    Same as usual    Less than usual    Much less than usual

7 Been able to enjoy your normal day to day activities?

More than usual    Same as usual    Less than usual    Much less than usual

2 Lost much sleep over worry?

More than usual    Same as usual    Less than usual    Much less than usual

8 Been able to face up to your problems?

More than usual    Same as usual    Less than usual    Much less than usual

3 Felt that you were playing a useful part in things?

More than usual    Same as usual    Less than usual    Much less than usual

9 Been feeling unhappy or depressed?

Not at all    No more than usual    Rather more than usual    Much more than usual

4 Felt capable of making decisions about things?

More than usual    Same as usual    Less than usual    Much less than usual

10 Been losing confidence in yourself?

Not at all    No more than usual    Rather more than usual    Much more than usual

5 Felt constantly under strain?

Not at all    No more than usual    Rather more than usual    Much more than usual

11 Been thinking of yourself as a worthless person?

Not at all    No more than usual    Rather more than usual    Much more than usual

6 Felt you couldn't overcome difficulties?

Not at all    No more than usual    Rather more than usual    Much more than usual

12 Been feeling reasonably happy, all things considered?

More than usual    Same as usual    Less than usual    Much less than usual

13 How often have you sought your doctor's advice within the last 6 weeks? \_\_\_\_\_

14 Were any of those visits to seek advice about a problem you believe to be caused by stress? YES

# **BEST COPY NOTE**

**THE FOLLOWING PAGES  
ARE STUCK IN SUCH A  
MANNER THAT  
FILMING IS IMPEDED**

## Human Services Survey

| HOW OFTEN: | 0     | 1                                | 2                          | 3                         | 4                 | 5                        | 6            |
|------------|-------|----------------------------------|----------------------------|---------------------------|-------------------|--------------------------|--------------|
|            | Never | A few times<br>a year<br>or less | Once a<br>month<br>or less | A few<br>times a<br>month | Once<br>a<br>week | A few<br>times<br>a week | Every<br>day |

### HOW OFTEN

0 - 6

Statements:

1. \_\_\_\_\_ I feel emotionally drained from my work.
2. \_\_\_\_\_ I feel used up at the end of the workday.
3. \_\_\_\_\_ I feel fatigued when I get up in the morning and have to face another day on the job.
4. \_\_\_\_\_ I can easily understand how my recipients feel about things.
5. \_\_\_\_\_ I feel I treat some recipients as if they were impersonal objects.
6. \_\_\_\_\_ Working with people all day is really a strain for me.
7. \_\_\_\_\_ I deal very effectively with the problems of my recipients.
8. \_\_\_\_\_ I feel burned out from my work.
9. \_\_\_\_\_ I feel I'm positively influencing other people's lives through my work.
10. \_\_\_\_\_ I've become more callous toward people since I took this job.
11. \_\_\_\_\_ I worry that this job is hardening me emotionally.
12. \_\_\_\_\_ I feel very energetic.
13. \_\_\_\_\_ I feel frustrated by my job.
14. \_\_\_\_\_ I feel I'm working too hard on my job.
15. \_\_\_\_\_ I don't really care what happens to some recipients.
16. \_\_\_\_\_ Working with people directly puts too much stress on me.
17. \_\_\_\_\_ I can easily create a relaxed atmosphere with my recipients.
18. \_\_\_\_\_ I feel exhilarated after working closely with my recipients.
19. \_\_\_\_\_ I have accomplished many worthwhile things in this job.
20. \_\_\_\_\_ I feel like I'm at the end of my rope.
21. \_\_\_\_\_ In my work, I deal with emotional problems very calmly.
22. \_\_\_\_\_ I feel recipients blame me for some of their problems.

(Administrative use only)

cat.

cat.

cat.

EE: \_\_\_\_\_ DP: \_\_\_\_\_ PA: \_\_\_\_\_



**APPENDIX II f - Fear of Death Questionnaire - (Howells, Gould and Field, 1986) - 2.2.2.iii - 5**

Please rate the degree of fear you associate with each of the following concepts.

- 1 The thought of dying yourself (the process of dying rather than what comes after death)

Not fearful at all   1   2   3   4   5   6   7   extremely fearful

- 2 The thought of being dead.

Not fearful at all   1   2   3   4   5   6   7   extremely fearful

- 3 The thought of someone close to you dying.

Not fearful at all   1   2   3   4   5   6   7   extremely fearful

- 4 The thought of talking with a dying patient about his/her condition during your work.

Not fearful at all   1   2   3   4   5   6   7   extremely fearful

- 5 How frequently do you think about dying yourself (ie the process of dying rather than what comes after)?

Very rarely   1   2   3   4   5   almost every day

- 6 How frequently do you think about being dead yourself?

Very rarely   1   2   3   4   5   almost every day

- 7 How frequently do you think about someone close to you dying?

Very rarely   1   2   3   4   5   almost every day

- 8 How frequently do you think about the imminent death of your patient?

Very rarely   1   2   3   4   5   almost every day

## APPENDIX II g - Coping With Death Scale - (Bugen, 1980 - 81) - 2.2.2.iii - 6

Please rate on a scale of 1 to 7 how much you agree or disagree

1                      2                      3                      4                      5                      6                      7

Do not  
agree  
at all

Neutral

Agree  
completely

- 1 Thinking about death is a waste of time \_\_\_\_\_
- 2 I have a good perspective on death and dying \_\_\_\_\_
- 3 Death is an area that can be dealt with safely \_\_\_\_\_
- 4 I am aware of the full array of service from funeral companies \_\_\_\_\_
- 5 I am aware of the variety of options for disposing of bodies \_\_\_\_\_
- 6 I am aware of the full array of emotions which characterise human grief \_\_\_\_\_
- 7 Knowing that I will surely die does not in any way affect the conduct of my life \_\_\_\_\_
- 8 I feel prepared to face my death \_\_\_\_\_
- 9 I feel prepared to face my dying process \_\_\_\_\_
- 10 I understand my death-related fears \_\_\_\_\_
- 11 I am familiar with prearrangement of funerals \_\_\_\_\_
- 12 Lately I find it OK to think about death \_\_\_\_\_
- 13 My attitude about living has recently changed \_\_\_\_\_
- 14 I can express my fears about dying \_\_\_\_\_
- 15 I can put words to my gut-level feelings about death and dying \_\_\_\_\_
- 16 I am making the best of my present life \_\_\_\_\_
- 17 The quality of my life matters more than the length of it \_\_\_\_\_
- 18 I can talk about my death with family and friends \_\_\_\_\_
- 19 I know who to contact when death occurs \_\_\_\_\_
- 20 I will be able to cope with future losses \_\_\_\_\_
- 21 I feel able to handle the death of others close to me \_\_\_\_\_
- 22 I know how to listen to others, including the terminally ill \_\_\_\_\_
- 23 I know how to speak to children about death \_\_\_\_\_
- 24 I may say the wrong thing when I am with someone mourning \_\_\_\_\_
- 25 I am able to spend time with the dying if I need to \_\_\_\_\_
- 26 I can help people with their thoughts and feelings about death and dying \_\_\_\_\_
- 27 I would be able to talk to a friend or family member about his or her death \_\_\_\_\_
- 28 I can lessen the anxiety of those around me when the topic is death and dying \_\_\_\_\_
- 29 I can communicate with the dying \_\_\_\_\_
- 30 I can tell people, before I or they die, how much I love them \_\_\_\_\_

**APPENDIX II h - Death Self-Efficacy Scale - (Robbins, 1992) - 2.2.2.iii - 7**

For each of the items below please rate how certain or uncertain you are that you can perform each one, using this scale.

|           |   |   |            |   |   |   |            |   |   |    |
|-----------|---|---|------------|---|---|---|------------|---|---|----|
| 0         | 1 | 2 | 3          | 4 | 5 | 6 | 7          | 8 | 9 | 10 |
| Highly    |   |   | Moderately |   |   |   | Completely |   |   |    |
| Uncertain |   |   | Certain    |   |   |   | Certain    |   |   |    |

- 1 Understand the limits of your role as a nurse \_\_\_\_\_
- 2 Be sensitive to the needs of your patient and family \_\_\_\_\_
- 3 Buy life insurance \_\_\_\_\_
- 4 Allow the patient and his/her family to support you \_\_\_\_\_
- 5 Handle the death of a grandparent \_\_\_\_\_
- 6 Listen to the concerns of a dying patient \_\_\_\_\_
- 7 Listen to the family of a dying patient \_\_\_\_\_
- 8 Touch a dead body \_\_\_\_\_
- 9 Identify the concerns of a dying patient and his/her family \_\_\_\_\_
- 10 Communicate with other staff about your patient(s) \_\_\_\_\_
- 11 Get a medical check-up \_\_\_\_\_
- 12 Handle the illness of your child \_\_\_\_\_
- 13 Handle knowing that a family member has a fatal condition \_\_\_\_\_
- 14 Provide physical care for a dying patient \_\_\_\_\_
- 15 Assist in transporting a dying patient \_\_\_\_\_
- 16 Prepare your will \_\_\_\_\_
- 17 Run errands for a patient \_\_\_\_\_
- 18 Listen to a news report about multiple deaths \_\_\_\_\_
- 19 Communicate with a dying patient \_\_\_\_\_
- 20 Ask someone close to you if s/he has a terminal illness \_\_\_\_\_
- 21 Allow a patient to communicate fully \_\_\_\_\_
- 22 Purchase your own cemetery plot \_\_\_\_\_
- 23 Cope with the death of your mother \_\_\_\_\_
- 24 Ask whether you have a terminal illness \_\_\_\_\_
- 25 Cope with the death of your father \_\_\_\_\_
- 26 Visit a dying friend \_\_\_\_\_
- 27 Provide emotional support for the patient's family \_\_\_\_\_
- 28 Care for the patient so the family can have some respite \_\_\_\_\_
- 29 Go to a morgue \_\_\_\_\_
- 30 Write a Living Will \_\_\_\_\_
- 31 Understand the philosophy of hospice care \_\_\_\_\_
- 32 Plan your funeral service \_\_\_\_\_
- 33 Sign a card to be an organ donor \_\_\_\_\_
- 34 Attend a funeral/wake where the casket is open \_\_\_\_\_
- 35 Understand bereavement and grief \_\_\_\_\_
- 36 Cope with the death of your child \_\_\_\_\_
- 37 Handle the death of your spouse/partner \_\_\_\_\_
- 38 Cope with the death of a friend the same age as you \_\_\_\_\_
- 39 Tolerate spiritual and religious differences \_\_\_\_\_
- 40 Cope with the death of your pet \_\_\_\_\_
- 41 Care for yourself if you are experiencing stress in caring for a dying patient \_\_\_\_\_
- 42 Be with a person at the time of death \_\_\_\_\_
- 43 Be with a person experiencing unpleasant physical symptoms \_\_\_\_\_
- 44 Prepay your funeral \_\_\_\_\_

**APPENDIX II i - Accumulated Loss Phenomenon Questionnaire - (Adams, Hershatter and Moritz, 1991)**

- 2.2.2.iii - 8

Please circle the number which best represents how you feel about each of the statements.

1 = Strongly agree/frequently, 2 = Agree/sometimes, 3 = Neutral, 4 = Disagree/seldom, and  
5 = Strongly disagree/Never

|  |   |   |   |   |   |
|--|---|---|---|---|---|
| 1 I often remember the death of a family member or loved one   | 1 | 2 | 3 | 4 | 5 |
| 2 I identify with patients/families who are similar to my own  | 1 | 2 | 3 | 4 | 5 |
| 3 Some patients/families remind me of someone I lost   | 1 | 2 | 3 | 4 | 5 |
| 4 I think having had a personal loss makes my work harder  | 1 | 2 | 3 | 4 | 5 |
| 5 This makes it more difficult to care for those patients/families                                   | 1 | 2 | 3 | 4 | 5 |
| 6 I like to be with patients when they die   | 1 | 2 | 3 | 4 | 5 |
| 7 I often think of my own death  | 1 | 2 | 3 | 4 | 5 |
| 8 I feel comfortable dealing with everyday stresses  | 1 | 2 | 3 | 4 | 5 |
| 9 I am aware of the hope of patients/families to have a good death                                   | 1 | 2 | 3 | 4 | 5 |
| 10 I am stressed because I expect too much of myself   | 1 | 2 | 3 | 4 | 5 |
| 11 I am bothered by feelings of inadequacy   | 1 | 2 | 3 | 4 | 5 |
| 12 I struggle with the conflict between ideals and reality   | 1 | 2 | 3 | 4 | 5 |
| 13 I feel guilty when my daily work ideals are not achieved  | 1 | 2 | 3 | 4 | 5 |
| 14 I have become desensitised to death   | 1 | 2 | 3 | 4 | 5 |
| 15 I expect too high a standard from my co-workers   | 1 | 2 | 3 | 4 | 5 |
| 16 I feel rewarded and acknowledged for my work with patients/families                               | 1 | 2 | 3 | 4 | 5 |
| 17 I feel rewarded and acknowledged for my work by my co-workers                                     | 1 | 2 | 3 | 4 | 5 |
| 18 I feel rewarded and acknowledged for my work by my Head Nurse                                     | 1 | 2 | 3 | 4 | 5 |
| 19 I expect more support than I get from members of other disciplines                                | 1 | 2 | 3 | 4 | 5 |
| 20 I feel confident with my nursing leadership   | 1 | 2 | 3 | 4 | 5 |
| 21 I feel confident with our medical leadership  | 1 | 2 | 3 | 4 | 5 |
| 22 I am troubled by my personal dislike of some patients/families                                    | 1 | 2 | 3 | 4 | 5 |
| 23 I feel impatient with over-grieving families  | 1 | 2 | 3 | 4 | 5 |
| 24 I find myself steering conversations with patients/families to stay on superficial topics         | 1 | 2 | 3 | 4 | 5 |
| 25 I avoid approaching tearful or emotional families   | 1 | 2 | 3 | 4 | 5 |
| 26 I am uncomfortable with hostility in patients/families  | 1 | 2 | 3 | 4 | 5 |
| 27 The dying patient who talks about his/her death is difficult to care for                          | 1 | 2 | 3 | 4 | 5 |
| 28 I worry that I have hastened the death of a patient   | 1 | 2 | 3 | 4 | 5 |
| 29 The younger the patient, the harder I find it to care for him/her                                 | 1 | 2 | 3 | 4 | 5 |
| 30 The more disfigured the patient, the harder I find it to care for him/her                         | 1 | 2 | 3 | 4 | 5 |
| 31 I am more comfortable with elderly patients   | 1 | 2 | 3 | 4 | 5 |
| 32 I would rather care for an unresponsive patient who is dying than one who is conscious            | 1 | 2 | 3 | 4 | 5 |
| 33 If so, it bothers me to have these feelings   | 1 | 2 | 3 | 4 | 5 |
| 34 I feel uncomfortable and inadequate with confused patients  | 1 | 2 | 3 | 4 | 5 |
| 35 A nurse should never let a patient know s/he is upset by her/his condition                        | 1 | 2 | 3 | 4 | 5 |
| 36 The one-to-one relationship between a patient and a nurse is the most important aspect of nursing | 1 | 2 | 3 | 4 | 5 |
| 37 I dread admissions for fear of bonding with them  | 1 | 2 | 3 | 4 | 5 |
| 38 I dread admissions because of the lack of closure with a previous patient                         | 1 | 2 | 3 | 4 | 5 |
| 39 When working with another nurse I am less involved in the patient's care                          | 1 | 2 | 3 | 4 | 5 |
| 40 There are times when I need another nurse with me, for help with physical or emotional issues     | 1 | 2 | 3 | 4 | 5 |
| 41 Often I don't recognise bereaved families when I see them later                                   | 1 | 2 | 3 | 4 | 5 |
| 42 If so, this makes me feel guilty  | 1 | 2 | 3 | 4 | 5 |

(cont...)

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| 43 I get to the point where many patients look alike to me  | 1 | 2 | 3 | 4 | 5 |
| 44 I address a patient by a name belonging to a former patient who died                               | 1 | 2 | 3 | 4 | 5 |
| 45 I feel overwhelmed by patient/family needs   | 1 | 2 | 3 | 4 | 5 |
| 46 I avoid passing the bed of a very needy patient/family   | 1 | 2 | 3 | 4 | 5 |
| 47 I am bothered by the lack of time to grieve after a patient's death                                | 1 | 2 | 3 | 4 | 5 |
| 48 I feel a sense of personal loss from a patient death where I have<br>been very much involved       | 1 | 2 | 3 | 4 | 5 |
| 49 I dream about the patients or their families   | 1 | 2 | 3 | 4 | 5 |
| 50 I dream about work situations  | 1 | 2 | 3 | 4 | 5 |
| 51 I think about patients/ families when I leave work   | 1 | 2 | 3 | 4 | 5 |
| 52 I have difficulty leaving work on time   | 1 | 2 | 3 | 4 | 5 |
| 53 I skip lunch or breaks to do my work better  | 1 | 2 | 3 | 4 | 5 |
| 54 I avoid staff meetings where staff stress will be addressed  | 1 | 2 | 3 | 4 | 5 |
| 55 I attend fewer wakes or funerals outside work now  | 1 | 2 | 3 | 4 | 5 |
| 56 I dread going to bereavement functions   | 1 | 2 | 3 | 4 | 5 |
| 57 I call in sick when stressed or fed up   | 1 | 2 | 3 | 4 | 5 |
| 58 I feel I am not keeping up with advances in medical treatments                                     | 1 | 2 | 3 | 4 | 5 |
| 59 I have difficulty in letting go of events at work and becoming<br>involved in something after work | 1 | 2 | 3 | 4 | 5 |
| 60 I find my work interferes with my relationships with others  | 1 | 2 | 3 | 4 | 5 |
| 61 I consciously turn off work when I get home  | 1 | 2 | 3 | 4 | 5 |
| 62 I feel work-related stress affects my family relationships   | 1 | 2 | 3 | 4 | 5 |
| 63 I discuss work-related issues with friends and family  | 1 | 2 | 3 | 4 | 5 |
| 64 I talk about death more with friends and family  | 1 | 2 | 3 | 4 | 5 |
| 65 I call in on my time off to see how a patient is doing   | 1 | 2 | 3 | 4 | 5 |
| 66 Most of my friends are people I work with  | 1 | 2 | 3 | 4 | 5 |
| 67 I enjoy investing in new staff   | 1 | 2 | 3 | 4 | 5 |
| 68 I dread investing in new staff for fear of losing them   | 1 | 2 | 3 | 4 | 5 |
| 69 I feel loss of staff as much as death of a patient   | 1 | 2 | 3 | 4 | 5 |
| 70 I feel I have a closer relationship with co-workers here than in previous jobs                     | 1 | 2 | 3 | 4 | 5 |
| 71 I feel valued, respected and supported by my co-workers  | 1 | 2 | 3 | 4 | 5 |
| 72 I value, respect and support my co-workers   | 1 | 2 | 3 | 4 | 5 |
| 73 I think about getting cancer   | 1 | 2 | 3 | 4 | 5 |
| 74 I dread disfigurement from cancer  | 1 | 2 | 3 | 4 | 5 |
| 75 I dread pain from cancer   | 1 | 2 | 3 | 4 | 5 |
| 76 I am able to cry in times of stress  | 1 | 2 | 3 | 4 | 5 |
| 77 I find crying helps me with stress   | 1 | 2 | 3 | 4 | 5 |
| 78 Smaller losses take on greater significance now  | 1 | 2 | 3 | 4 | 5 |
| 79 I have a sense of carrying a burden of accumulated losses at work                                  | 1 | 2 | 3 | 4 | 5 |
| 80 I exercise regularly   | 1 | 2 | 3 | 4 | 5 |
| 81 I eat well-balanced meals  | 1 | 2 | 3 | 4 | 5 |
| 82 I sleep well   | 1 | 2 | 3 | 4 | 5 |
| 83 I am involved in outside activities, interests and hobbies   | 1 | 2 | 3 | 4 | 5 |
| 84 I care for my body differently since working with patients who<br>are seriously ill or dying       | 1 | 2 | 3 | 4 | 5 |
| 85 I find this work experience makes me 'live for the day'  | 1 | 2 | 3 | 4 | 5 |
| 86 I find this work experience makes me be more positive and outgoing                                 | 1 | 2 | 3 | 4 | 5 |
| 87 I find I make more short term goals  | 1 | 2 | 3 | 4 | 5 |
| 88 The rewards of my job outweigh the disadvantages   | 1 | 2 | 3 | 4 | 5 |
| 89 I think anger is a negative feeling  | 1 | 2 | 3 | 4 | 5 |
| 90 I recognise anger in myself  | 1 | 2 | 3 | 4 | 5 |
| 91 I am uncomfortable with the anger of others.   | 1 | 2 | 3 | 4 | 5 |

# APPENDIX IIj - Supplementary questions

## PLEASE ANSWER THE FOLLOWING QUESTIONS

1 What losses at work, aside from death-related ones, affect you most?

2 What is your main frustration at work?

3 What aspect of your work is least rewarding?

4 What aspect of your work is most rewarding?

Questions regarding social support:

Please circle the person or people from whom you gain support

|                   |                               |  |                      |
|-------------------|-------------------------------|--|----------------------|
| Spouse or partner | Close friend<br>(not related) | Close friend who<br>is a family member | nursing<br>colleague |
|-------------------|-------------------------------|--|----------------------|

When dealing with stress which is related to work, to whom do you turn for support?

|                   |         |            |                   |
|-------------------|---------|------------|-------------------|
| Spouse or partner | friends | colleagues | professional help |
|-------------------|---------|------------|-------------------|

**APPENDIX III - General Population Survey of Fear of Death - Study 2 - (2.2.4.iii)**  
**RESEARCH PROJECT AT NENE COLLEGE, NORTHAMPTON**

At Nene College in Northampton, research is underway to study stress and death attitudes in nurses. One of the most stressful parts of a nurse's work is having to care for the critically ill and dying patient. When someone is very ill or dying, we expect the nurse to be very caring and supportive, not only to the patient but to the family and relatives. Part of this study is aimed at finding out how nurses think about death and dying and how their attitudes affect their ability to do this part of their work.

In this regard nurses have been asked to answer the questions which are on the other side of this form. In order to know whether the nurses attitudes are similar to or different from the attitudes generally held by the rest of the population, it is necessary to ask what the attitudes of the general public are. So, to this end, I would be very grateful if one adult (18 yrs or over) would complete this form and return it to the research centre in the enclosed prepaid envelope. **THERE IS NO NEED TO APPLY A STAMP TO THE ENVELOPE.**

The information requested about your age, occupation etc, is simply used to determine whether those replying to the questions are a representative sample of the general public.

**THANK YOU FOR YOUR TIME AND COOPERATION.**

**QUERIES TO Mrs Sylvia McNeely, Research, Nene College, Moulton Park,  
 Northampton**

-----  
 Please tick as appropriate

AGE 1 18 to 30 \_\_\_\_\_  
 2 31 to 40 \_\_\_\_\_  
 3 41 to 50 \_\_\_\_\_  
 4 51 to 65 \_\_\_\_\_  
 5 over 65 \_\_\_\_\_

GENDER 1 Male \_\_\_\_\_  
 2 Female \_\_\_\_\_

Please give your occupation \_\_\_\_\_

Please give the occupation of head of household (if unemployed, what would it be if working) \_\_\_\_\_

Do you live alone or with other adults? \_\_\_\_\_

Have you been bereaved within the last six months? YES \_\_\_\_\_  
 NO \_\_\_\_\_

Please accept my apologies if this has caused you any additional unhappy feelings.  
 (cont...)

## PLEASE CIRCLE THE APPROPRIATE NUMBER

Please rate the degree of fear you associate with each of the following concepts:

- 1 The thought of dying yourself ( the process of dying rather than what comes after death.

Not fearful  
at all      1    2    3    4    5    6    7      extremely  
fearful

- 2 The thought of being dead yourself.

Not fearful  
at all      1    2    3    4    5    6    7      extremely  
fearful

- 3 The thought of someone close to you dying.

Not fearful  
at all      1    2    3    4    5    6    7      extremely  
fearful

- 4 How frequently do you think about dying yourself ( the process of dying rather than what comes after death)?

Very rarely    1    2    3    4    5    6    7    almost every day

- 5 How frequently do you think about being dead?

Very rarely    1    2    3    4    5    6    7    almost every day

- 6 How frequently do you think about someone close to you dying?

Very rarely    1    2    3    4    5    6    7    almost every day.



#### **APPENDIX IV - Questions for Interview study of nurses - Study 1, Phase 2 - (2.2.3.iii)**

Sample of questions used in semi-structured interviews for Palliative care and General groups - see below for Psychiatric group:

“In this interview I hope to gather information from you about your own personal experience of stress at work and about how you deal with that stress. I intend to ask about your experience of some specific aspects of your work such as patient death and changes in the working environment. I will also invite you to comment on how you think things could be improved at work to enable nurses to do their work better but also with fewer negative effects of stress.

Please remember that all information will be treated anonymously to protect your privacy and the only other person who may or may not hear these recordings is a person who assists with the transcription of tapes, and who will have no other part in this research and will have no way of knowing the identity of the speaker on the tape.”

(Above read verbatim to each interviewee)

Would you please describe the unit in which you work?

What other areas of nursing have you worked in?

Would you describe your job as stressful? If so, why?

If someone asked what caused you the most stress at work, what would you say?

Do you find most stress comes from single incidents or from an accumulation of things?

What are the major emotional issues which you face in your work?

When you become aware that a patient has been diagnosed as terminally ill, what effect does that have on you...on your relationship with that patient.....with other patients?

Are you aware of preparing yourself for the impending death?...if so, how?

How frequently do you experience patient death?

Do you ever find that you are not over one death before you have to cope with the next one? If so, what effect does this have on you?

What do you do to help you cope with these situations?

Is the stress of dealing with the dying and patient death the same or different from stress associated with things like workload, staff difficulties, etc?

How does patient death affect your own feelings about death and dying? Your own feelings affect your work with dying patients? (cont...)

What effect does this work have on your relationships with others ie family, friends?

Do you discuss your work with family and friends?

Do you feel able to cope with death and dying issues at work?...In personal terms?

What do you think accounts for your confidence/lack of confidence that you can cope?

How would you like your training to have been different in this respect?

Is there a particular reason why you have chosen this area of nursing work?

Could you describe the positive aspects of your job?

Realistically, how do you think the stress of your job could be reduced?

Do you have suggestions for improving training for nurses?

What kind of support do you have to help you cope with stress?

Do you feel that there is adequate support to help nurses cope with the stress of work?  
What kinds of support would you like to see in place?

For Psychiatric nurses - where appropriate, questions from above, plus the following:

Could you describe how you think nurse/patient relationships differ in your area of work, from those in, say, general nursing?

How does your work experience affect your relationships with your family, friends, etc?

The quality of life enjoyed by patients is no doubt an issue for all nurses, but especially for palliative care nurses. What are the implications for your area of nursing?

Does your work affect how you feel about life and death and dying issues?

**APPENDIX Va - Letter sent with Diary, Study 1, Phase 2 - (2.2.3.iii)**

TO:

Date

Dear M

Thank you for agreeing to participate in the second phase of this research project. You have been selected to complete a diary for ten consecutive working days (diary enclosed).

You will see that it is fairly self-explanatory. If you feel at the end of a day that you have not experienced any stressful incidents, please leave the page blank. You are asked to complete 10 consecutive working days so there could be days off in the middle. Please remember to return to the diary after any break of that kind.

For the purposes of this diary 'stressful' is defined as causing you worry, making you feel pressured or anxious'.

I am indebted to you for your assistance in this research and I would be very grateful for any comments you care to make on the last page of the diary.

When you have completed your diary, please return it to me in the envelope provided.

Again, my thanks, and very best wishes.

Yours sincerely

Sylvia A McNeely (Mrs)  
Research Student

**APPENDIX Vb - Diary - Study 1 Phase 2 - 2.2.3.iii**

**RESEARCH PROJECT ON STRESS AND DEATH**

**ATTITUDES IN NURSES**

**DAILY DIARY**

**TO BE RETURNED TO**

**SYLVIA McNEELY  
THE RESEARCH CENTRE  
NENE COLLEGE  
BOUGHTON GREEN ROAD  
NORTHAMPTON NN2 7AL**

**(cont)**

DAILY DIARY:

DATE OF FIRST ENTRY:.....

DATE OF LAST ENTRY:.....

You will find overleaf some instructions, a form to record some biographical information, two pages to make notations for each of ten days and a final page for you to make any other comments.

I look forward to reading your thoughts and comments and I am grateful to you for taking the time to complete this diary for my research.

(cont...)

## BIOGRAPHICAL INFORMATION

Please tick as appropriate:

Age range: 1 under 30 \_\_\_\_\_  
2 31 - 40 \_\_\_\_\_  
3 41 - 50 \_\_\_\_\_  
4 51 - 65 \_\_\_\_\_

Gender 1 Male \_\_\_\_\_  
2 Female \_\_\_\_\_

In which area of nursing do you work? 1 Palliative care \_\_\_\_\_  
2 Psychiatric \_\_\_\_\_  
3 General nursing \_\_\_\_\_

Number of hours worked per week 1 less than 15 \_\_\_\_\_  
2 15 - 25 \_\_\_\_\_  
3 26 - 40 \_\_\_\_\_

Please give your nursing grade \_\_\_\_\_

Thank you for your valuable contribution to this research project.

(cont...)

**DAILY DIARY TO BE COMPLETED EACH DAY FOR 10 CONSECUTIVE  
WORKING DAYS**

Thank you for agreeing to participate in my study of stress and death attitudes.

In this diary you are asked to record **ON A DAILY BASIS** information about stressful incidents at work and how those events affect you **AND YOUR WORK**.

Here are some examples:

Most stressful incident:

Mrs M in terrible pain - could not contact the doctor to alter her medication.

Effect:

Felt anxious and upset - angry too - you can never get hold of him and he doesn't keep us informed. It was hard to think of other patients' needs with Mrs M so upset.

Other stressful incidents:

Ran out of regular bandages - there's never enough! Sister bit my head off about the paperwork - too much of that! Mrs W waited all day to be discharged - she got angrier and angrier at me until I hardly wanted to go near her.

Effect:

It all adds up to make you feel you are banging your head against a brick wall - frustrated and angry about the mountain of paper and the shortage of equipment and fed up and resentful about the patients shouting at me for something I cannot control.

(cont...)

**(NOTE PAGES FOR DAY ONE TO TEN WERE AS THIS SAMPLE)**

**DAY TEN**

**MOST STRESSFUL INCIDENT**

**EFFECT**

**OTHER STRESSFUL INCIDENTS**

**EFFECT**

**(cont...)**



If you have experienced the death of one of your patients today, please answer the following:

1 Was this the most stressful incident at work today? IF YOU HAVE ALREADY WRITTEN ABOUT THIS, PLEASE GO TO QUESTION 3. OTHERWISE PLEASE CONTINUE.

2 How did this event affect your work for the remainder of the day?

3 What effect does this kind of experience have on your personal feelings about death and dying (or vice versa ie how do your personal feelings affect the way you deal with such an event)?

(cont...)

PLEASE USE THIS PAGE TO MAKE ANY COMMENTS YOU HAVE ABOUT STRESS AT WORK, HOW YOU COPE, WORKING WITH THE DYING OR THIS RESEARCH PROJECT.

COULD YOU MAKE ANY SUGGESTIONS FOR IMPROVEMENT TO TRAINING FOR NURSES (ESPECIALLY REGARDING DEATH AND DYING ISSUES) OR FOR REALISTIC WAYS IN WHICH THE WORKPLACE COULD BE CHANGED TO REDUCE STRESS FOR NURSES?

**APPENDIX VI - Factor Analysis Results - Death Self-Efficacy (6.3.1)**

Factor Analysis of Death Self-Efficacy (DSE) - varimax rotation, factors having eigenvalues &gt; 1

| ITEM (% of the variance) | LOADING (only >.5) | STATEMENT   |
|--------------------------|--------------------|---|
| FACTOR 1<br>(26.5%)      |                    |   |
| DSE7                     | .836               | Listen to the family of a dying patient                     |
| DSE6                     | .787               | Listen to the concerns of a dying patient                   |
| DSE19                    | .756               | Communicate with a dying patient                            |
| DSE9                     | .689               | Identify the concerns of a dying patient and his/her family |
| DSE21                    | .630               | Allow a patient to communicate fully                        |
| DSE27                    | .578               | Provide emotional support for the patient's family          |
| DSE2                     | .528               | Be sensitive to the needs of the family                     |
| FACTOR 2<br>(8.2%)       |                    |   |
| DSE23                    | .810               | Cope with the death of your mother                          |
| DSE 37                   | .790               | Handle the death of your spouse/partner                     |
| DSE25                    | .787               | Cope with the death of your father                          |
| DSE38                    | .721               | Cope with the death of a friend the same age as you         |
| DSE36                    | .665               | Cope with the death of your child                           |
| DSE24                    | .531               | Ask whether you have a terminal illness                     |
| DSE40                    | .519               | Cope with the death of your pet                             |
| DSE13                    | .513               | Handle knowing that a family member has a fatal condition   |
| DSE26                    | .511               | Visit a dying friend  |
| FACTOR 3<br>(4.9%)       |                    |   |
| DSE32                    | .771               | Plan your funeral service                                   |
| DSE30                    | .760               | Write a Living Will   |
| DSE44                    | .709               | Prepay your funeral   |
| DSE22                    | .688               | Purchase your own cemetery plot                             |
| DSE16                    | .610               | Prepare your will   |
| FACTOR 4<br>(4.2%)       |                    |   |
| DSE8                     | .767               | Touch a dead body   |
| DSE14                    | .647               | Provide physical care for a dying patient                   |
| DSE15                    | .622               | Assist in transporting a dying patient                      |
| DSE42                    | .551               | Be with a person at the time of death                       |
| FACTOR 5<br>(3.9%)       |                    |   |
| DSE17                    | .761               | Run errands for a patient                                   |
| DSE28                    | .700               | Care for the patient so the family can have some respite    |
| FACTOR 6<br>(2.9%)       |                    |   |
| DSE39                    | .649               | Tolerate spiritual and religious differences                |
| FACTOR 7<br>(2.9%)       |                    |   |
| DSE34                    | .757               | Attend a funeral/wake where the casket is open              |
| FACTOR 8<br>(2.7%)       |                    |   |
| DSE1                     | .711               | Understand the limits of your role as a nurse               |
| DSE2                     | .534               | Be sensitive to the needs of the patient and family         |
| FACTOR 9<br>(2.6%)       |                    |   |
| dse18                    | .654               | Listen to a news report of multiple deaths                  |
| FACTOR 10<br>(2.4%)      |                    |   |
| DSE11                    | .801               | Get a medical check-up                                      |
| DSE3                     | .540               | Buy life assurance  |
| FACTOR 11<br>(2.3%)      |                    |   |
| DSE12                    | .731               | Handle the illness of your child                            |

Total of 63.5% of variance explained by 11 factors

# **APPENDIX VII - Factor Analysis Results - Coping With Death (6.3.1)**

Factor Analysis of Coping With Death (CD) - varimax rotation, factors having eigenvalues > 1

| ITEM (% of variance)     | LOADING (only >.5) | STATEMENT   |
|--------------------------|--------------------|---|
| <b>FACTOR 1 (31.0 %)</b> |                    |   |
| CD26                     | .808               | I can help people with their thoughts and feelings about death and dying      |
| CD29                     | .773               | I can communicate with the dying  |
| CD27                     | .715               | I would be able to talk to a family member about his/her death                |
| CD28                     | .704               | I can lessen the anxiety of those around me when the topic is death and dying |
| CD22                     | .667               | I know how to listen to others including the terminally ill                   |
| CD23                     | .594               | I know how to speak to children about death                                   |
| CD25                     | .581               | I am able to spend time with the dying if I need to                           |
| CD30                     | .534               | I can tell people, before they die, how much I love them                      |
| <b>FACTOR 2 (7.2%)</b>   |                    |   |
| CD5                      | .764               | I am aware of the variety of options for disposal of bodies                   |
| CD11                     | .763               | I am familiar with the prearrangement of funerals                             |
| CD4                      | .752               | I am aware of the full array of funeral services from funeral companies       |
| CD19                     | .633               | I know who to contact when death occurs                                       |
| <b>FACTOR 3 (5.9%)</b>   |                    |   |
| CD8                      | .818               | I feel prepared to face my death  |
| CD9                      | .795               | I feel prepared to face my dying process                                      |
| CD10                     | .593               | I understand my death related fears   |
| <b>FACTOR 4 (5.0%)</b>   |                    |   |
| CD15                     | .643               | I can put words to my gut-level feelings about death and dying                |
| CD14                     | .618               | I can express my fears about dying  |
| CD3                      | .608               | Death is an area to be dealt with safely                                      |
| CD2                      | .554               | I have a good perspective on death and dying                                  |
| <b>FACTOR 5 (4.5%)</b>   |                    |   |
| CD20                     | .826               | I will be able to cope with future losses                                     |
| CD21                     | .798               | I feel able to handle the death of others close to me                         |
| <b>FACTOR 6 (4.3%)</b>   |                    |   |
| CD1                      | .803               | Thinking about death is a waste of time                                       |
| <b>FACTOR 7 (3.7%)</b>   |                    |   |
| CD24                     | .735               | I may say the wrong thing when I am with someone in mourning                  |

Total of 61.6% variance explained by 7 factors

**APPENDIX VIII - Factor Analysis Results - Accumulated Loss Phenomenon (7.2.2)**

5-Factor Analysis of all 91 Accumulated loss Phenomenon (ALP) items using all data - varimax rotation

| FACTOR<br>% OF VARIANCE | LOADING<br>(only >.5) | STATEMENT   |
|-------------------------|-----------------------|---|
| <b>FACTOR 1 (11.1%)</b> |                       |   |
| ALP 51                  | .695                  | I think about patients/families when I leave work   |
| ALP 50                  | .633                  | I dream about work situations   |
| ALP 10                  | .608                  | I feel stressed because I expect too much of myself   |
| ALP 52                  | .598                  | I have difficulty leaving work on time  |
| ALP 60                  | .586                  | I find my work interferes with my relationships with others                                     |
| ALP 11                  | .578                  | I am bothered by feelings of inadequacy   |
| ALP 47                  | .570                  | I am bothered by the lack of time to grieve after a patient's death                             |
| ALP 49                  | .549                  | I dream about patients/families   |
| ALP 13                  | .537                  | I feel guilty when my daily work ideals are not achieved  |
| ALP 53                  | .533                  | I skip lunch or breaks to do my work better   |
| ALP 79                  | .531                  | I have a sense of carrying a burden of accumulated loss at work                                 |
| ALP 59                  | .508                  | I have difficulty in letting go of events at work and becoming involved in something after work |
| <b>FACTOR 2 (7.5%)</b>  |                       |   |
| ALP 38                  | .579                  | I dread admissions because of lack of closure with the last patient                             |
| ALP 25                  | .563                  | I avoid approaching tearful or emotional families   |
| ALP 37                  | .558                  | I dread admissions for fear of bonding  |
| ALP 46                  | .557                  | I avoid passing the bed of a very needy patient/family  |
| ALP 23                  | .537                  | I feel impatient with over-grieving families  |
| ALP 22                  | .531                  | I am troubled by my personal dislike of some patients/families                                  |
| ALP 26                  | .518                  | I am uncomfortable with hostility in patients/families  |
| ALP 24                  | .504                  | I find myself steering conversations with patients/families to stay on superficial topics       |
| <b>FACTOR 3 (4.5%)</b>  |                       |   |
| ALP 21                  | .700                  | I feel confident with our medical leadership  |
| ALP 17                  | .694                  | I feel rewarded and acknowledged for my work by my co-workers                                   |
| ALP 18                  | .675                  | I feel rewarded and acknowledged for my work by my Head Nurse                                   |
| ALP 20                  | .641                  | I feel confident with our nursing leadership  |
| ALP 16                  | .635                  | I feel rewarded and acknowledged for my work with patients/families                             |
| ALP 71                  | .535                  | I feel valued, respected and supported by my co-workers   |
| <b>FACTOR 4 (3.6%)</b>  |                       |   |
| ALP 86                  | .644                  | I find this work experience makes me be more positive and outgoing                              |
| ALP 81                  | .629                  | I eat well-balanced meals   |
| ALP 87                  | .593                  | I find I make more short term goals   |
| ALP 85                  | .592                  | I find this work experience makes me 'live for the day'   |
| ALP 80                  | .541                  | I exercise regularly  |
| ALP 84                  | .519                  | I care for my body differently since working with patients who are seriously ill or dying       |
| <b>FACTOR 5 (3.1%)</b>  |                       |   |
| ALP 75                  | .634                  | I dread pain from cancer  |

Total of 29.8% variance explained by 5 factors

**APPENDIX IXa - Factor Analysis Results - Accumulated Loss Phenomenon (7.2.2)**

5-Factor analysis of 35 ALP items using data from Palliative care group only - Varimax rotation

| FACTOR<br>(% OF VARIANCE) | LOADING<br>(only >.5) | STATEMENT  |
|---------------------------|-----------------------|--|
| FACTOR 1 (21.2%)          |                       |  |
| ALP10                     | .763                  | I am stressed because I expect too much of myself  |
| ALP 13                    | .731                  | I feel guilty when my daily work-ideals are not achieved                                     |
| ALP 11                    | .726                  | I am bothered by my feelings of inadequacy   |
| ALP 12                    | .667                  | I struggle with the conflict between ideals and reality, theory and practice                 |
| ALP 52                    | .583                  | I have difficulty leaving work on time   |
| ALP 59                    | .548                  | I have difficulty letting go of events at work and becoming involved in something after work |
| FACTOR 2 (10.5%)          |                       |  |
| ALP 60                    | .756                  | I find my work interferes with my relationships with others                                  |
| ALP 62                    | .689                  | I feel work-related stress affects my family relationships                                   |
| ALP 45                    | .604                  | I feel overwhelmed by patient/family needs   |
| ALP 37                    | .589                  | I dread admissions for fear of bonding with them   |
| ALP 59                    | .513                  | I have difficulty letting go of events at work and becoming involved in something after work |
| ALP 47                    | .512                  | I am bothered by the lack of time to grieve after a patient's death                          |
| ALP 24                    | .507                  | I find myself steering conversations with patients/families to stay on superficial topics    |
| FACTOR 3 (7.3%)           |                       |  |
| ALP 86                    | .762                  | I find this work-experience makes me 'live for the day'                                      |
| ALP 84                    | .675                  | I care for my body differently since working with patients who are seriously ill or dying    |
| ALP 77                    | .670                  | I find crying helps me with stress   |
| ALP 87                    | .662                  | I find I make more short term goals  |
| ALP 76                    | .661                  | I am able to cry in times of stress  |
| ALP 88                    | .529                  | The rewards of my job outweigh the disadvantages   |
| FACTOR 4 (6.3%)           |                       |  |
| ALP 18                    | .823                  | I feel rewarded and acknowledged for my work by my Head Nurse                                |
| ALP 17                    | .785                  | I feel rewarded and acknowledged for my work by my co-workers                                |
| ALP 16                    | .668                  | I feel rewarded and acknowledged for my work with patients/families                          |
| ALP 71                    | .599                  | I feel valued, respected and supported by my co-workers                                      |
| FACTOR 5 (4.9%)           |                       |  |
| ALP 50                    | .727                  | I dream about work situations  |
| ALP 49                    | .724                  | I dream about patients or their families   |
| ALP 71                    | .528                  | I feel valued, respected and supported by my co-workers                                      |

Total of 50.2% variance explained by 5 factors

# **APPENDIX IXb - Factor Analysis Results - Accumulated Loss Phenomenon (7.2.2)**

5-Factor Analysis of 35 ALP items using data from psychiatric group only - Varimax rotation

| FACTOR<br>(% of variance) | LOADING<br>(only >.5) | STATEMENT   |
|---------------------------|-----------------------|---|
| Factor 1 (21.2%)          |                       |   |
| ALP 51                    | .766                  | I think about patients/families when I leave work   |
| ALP 50                    | .740                  | I dream about work situations   |
| ALP 60                    | .702                  | I find my work interferes with my relationships with others                                     |
| ALP 59                    | .685                  | I have difficulty in letting go of events at work and becoming involved in something after work |
| ALP 12                    | .661                  | I struggle with the conflict between ideals and reality, theory and practice                    |
| ALP 52                    | .637                  | I have difficulty leaving work on time  |
| ALP 47                    | .606                  | I am bothered by the lack of time to grieve after a patient's death                             |
| ALP 62                    | .597                  | I feel work-related stress affects my family relationships                                      |
| ALP 53                    | .595                  | I skip lunch or breaks to do my work better   |
| ALP 13                    | .588                  | I feel guilty when my daily work ideals are not achieved  |
| ALP 64                    | .583                  | I talk about death more with friends and family   |
| FACTOR 2 (11.4%)          |                       |   |
| ALP 17                    | .821                  | I feel rewarded and acknowledged for my work by my co-workers                                   |
| ALP 16                    | .754                  | I feel rewarded and acknowledged for my work with patients/families                             |
| ALP 71                    | .754                  | I feel valued, respected and supported by co-workers  |
| ALP 18                    | .746                  | I feel rewarded and acknowledged for my work by my Head Nurse                                   |
| ALP 88                    | .652                  | The rewards of my job outweigh the disadvantages  |
| ALP 8                     | .548                  | I feel comfortable dealing with everyday work stresses  |
| FACTOR 3 (7.2%)           |                       |   |
| ALP 85                    | .815                  | I find this work experience makes me 'live for the day'   |
| ALP 86                    | .801                  | I find this work experience makes me be more positive and outgoing                              |
| ALP 84                    | .660                  | I care for my body differently since working with patients who are seriously ill or dying       |
| ALP 87                    | .639                  | I find I make more short term goals   |
| FACTOR 4 (5.9%)           |                       |   |
| ALP 77                    | .813                  | I find crying helps me with stress  |
| ALP 76                    | .804                  | I am able to cry in times of stress   |
| FACTOR 5 (5.6%)           |                       |   |
| ALP 23                    | .765                  | I feel impatient with over-grieving families  |
| ALP 24                    | .686                  | I find myself steering conversations with patients/families to stay on superficial topics       |
| ALP 37                    | .508                  | I dread admissions for fear of bonding with them  |

Total of 51.3% variance explained by 5 factors

### APPENDIX IXc - Factor Analysis Results - Accumulated Loss Phenomenon (7.2.2)

5-Factor Analysis of 35 ALP items using data from the general nursing group only - Varimax rotation

| FACTOR<br>(% OF VARIANCE) | LOADING<br>(only >.5) | STATEMENT   |
|---------------------------|-----------------------|---|
| FACTOR 1 (17.6%)          |                       |   |
| ALP 50                    | .766                  | I dream about work situations   |
| ALP 49                    | .620                  | I dream about patients/families   |
| ALP 51                    | .584                  | I think about patients/families when I leave work   |
| ALP 78                    | .574                  | Smaller losses take on more significance now  |
| ALP 52                    | .529                  | I have difficulty leaving work on time  |
| ALP 71                    | .515                  | I feel valued, respected and supported by my co-workers                                   |
| FACTOR 2 (11.5%)          |                       |   |
| ALP 12                    | .714                  | I struggle with the conflict between ideals and reality, theory and practice              |
| ALP 11                    | .700                  | I am bothered by feelings of inadequacy   |
| ALP 76                    | .678                  | I am able to cry in times of stress   |
| ALP 77                    | .631                  | I find crying helps me with stress  |
| ALP 13                    | .594                  | I feel guilty when my daily work ideals are not achieved                                  |
| ALP 47                    | .526                  | I am bothered by the lack of time to grieve after a patient's death                       |
| FACTOR 3 (7.3%)           |                       |   |
| ALP 87                    | .727                  | I find I make more short term goals   |
| ALP 85                    | .705                  | I find this work experience makes me 'live for the day'                                   |
| ALP 86                    | .607                  | I find this work experience makes me be more positive and outgoing                        |
| ALP 88                    | .590                  | The rewards of my job outweigh the disadvantages  |
| ALP 77                    | .535                  | I find crying helps me with stress  |
| ALP 76                    | .509                  | I am able to cry in times of stress   |
| ALP 84                    | .508                  | I care for my body differently since working with patients who are seriously ill or dying |
| FACTOR 4 (5.8%)           |                       |   |
| ALP 37                    | .618                  | I dread admissions for fear of bonding  |
| ALP 23                    | .605                  | I feel impatient with over-grieving families  |
| ALP 45                    | .551                  | I feel over-whelmed by patient/family needs   |
| ALP 24                    | .548                  | I find myself steering conversations with patient/families to stay on superficial topics  |
| ALP 60                    | .529                  | I find my work interferes with my relationships with others                               |
| FACTOR 5 (5.3%)           |                       |   |
| ALP 16                    | .742                  | I feel rewarded and acknowledged for my work with patients/families                       |
| ALP 17                    | .715                  | I feel rewarded and acknowledged for my work by my co-workers                             |

Total of 47.5% variance explained by 5 factors



# **APPENDIX X - Accumulated Loss Phenomenon - Chi-Square and Crosstabs (7.2.2)**

Accumulated Loss Phenomenon (ALP) items showing significant group difference in response: see notes below

| Item No | Statement  | Chi-Sq Stats<br>DF = 2 | Pall vs Psy<br>DF=1 | Psy vs Gen<br>DF=1 | Pall vs Gen<br>DF=1 | Group which agrees/ disagrees |
|---------|--|------------------------|---------------------|--------------------|---------------------|-------------------------------|
| 6       | I like to be with patients when they die                                       | 16.87,<br>p<.001       | 13.56<br>p<.001     | 8.41<br>p<.01      | NS                  | Psy disagrees                 |
| 9       | I am aware of the hope of patient/families to have a good death                | 10.49,<br>p<.01        | 8.40<br>p<.01       | 4.51<br>p<.05      | NS                  | Psy disagrees                 |
| 16      | I feel rewarded and acknowledged for my work with patients and families        | 26.46<br>p<.00001      | 20.93<br>p<.00001   | 12.93<br>p<.001    | NS                  | Psy disagrees                 |
| 17      | I feel rewarded and acknowledged for my work by my co-workers                  | 6.56,<br>p<.05         | 5.66<br>p<.02       | NS                 | NS                  | Pall agrees                   |
| 19      | I expect more support than I get from members of other disciplines             | 18.90,<br>p<.0001      | 17.32<br>p<.0001    | NS                 | 8.40<br>p<.01       | Pall disagrees                |
| 20      | I feel confident with our nursing leadership                                   | 17.55,<br>p<.001       | 17.57<br>p<.0001    | 4.48<br>p<.05      | NS                  | Psy disagrees                 |
| 21      | I feel confident with our medical leadership                                   | 37.66,<br>p<.00001     | 34.54<br>p<.00001   | NS                 | 20.83<br>p<.0001    | Pall agrees                   |
| 34      | I feel uncomfortable and inadequate with confused patients                     | 22.36,<br>p<.0001      | 21.60<br>p<.00001   | 14.92<br>p<.001    | NS                  | Psy disagrees                 |
| 41      | Often I don't recognise bereaved families when I see them later                | 17.07,<br>p<.001       | 17.10<br>p<.0001    | 5.78<br>p<.02      | NS                  | Psy disagrees                 |
| 42      | If so (If yes to 41), this makes me feel guilty                                | 21.02,<br>p<.0001      | 20.75<br>p<.0001    | 9.09<br>p<.01      | NS                  | Psy disagrees                 |
| 44      | I address a patient by a name belonging to a former patient who died           | 13.45,<br>p<.01        | 6.09<br>p<.02       | NS                 | 9.90<br>p<.01       | Pall agrees                   |
| 47      | I am bothered by the lack of time to grieve after a patient's death            | 6.75,<br>p<.05         | NS                  | 6.74<br>p<.01      | NS                  | Psy disagrees                 |
| 51      | I think about patients/families when I leave work                              | 8.71,<br>p<.02         | 7.09<br>p<.01       | 5.22<br>p<.05      | NS                  | Psy disagrees                 |
| 53      | I skip lunch or breaks to do my work better                                    | 11.49,<br>p<.01        | NS                  | 10.61<br>p<.01     | 6.04<br>p<.02       | Gen agrees                    |
| 57      | I call in sick when stressed or fed up   | 11.34,<br>p<.01        | 8.66<br>p<.01       | 6.17<br>p<.01      | NS                  | Psy agrees                    |
| 63      | I discuss work-related issues with friends and family                          | 9.04,<br>p<.02         | NS                  | NS                 | 9.03<br>p<.01       | Gen agrees                    |
| 64      | I talk about death more with friends and family                                | 8.11,<br>p<.02         | 8.11<br>p<.01       | NS                 | NS                  | Psy disagrees                 |
| 66      | Most of my friends are people I work with                                      | 6.31,<br>p<.05         | 5.90<br>p<.02       | NS                 | NS                  | Psy agrees                    |
| 67      | I enjoy investing in new staff   | 6.89,<br>p<.05         | NS                  | 6.30<br>p<.02      | NS                  | Gen disagree                  |
| 69      | I feel loss of staff as much as death of a patient                             | 17.06, p<.001          | 3.85<br>p<.05       | 17.05<br>p<.0001   | 5.62<br>p<.02       | Gen disagree                  |
| 70      | I feel I have a closer relationship with co-workers here than in previous jobs | 25.25,<br>p<.01        | 7.15<br>p<.01       | NS                 | 11.86<br>p<.001     | Pall agree                    |
| 72      | I value, respect and support my co-workers                                     | 7.03,<br>p<.05         | 5.67<br>p<.02       | NS                 | NS                  | Pall agree                    |

See continuation, next page

Continuation :

|    |   |                   |                  |               |               |                 |
|----|---|-------------------|------------------|---------------|---------------|-----------------|
| 73 | I think about getting cancer  | 20.29,<br>p<.0001 | 19.93<br>p<.0001 | NS            | 7.81<br>p<.01 | Pall<br>agree   |
| 74 | I dread disfigurement from cancer   | 18.72,<br>p<.0001 | 18.38<br>p<.0001 | NS            | 6.54<br>p<.02 | Pall<br>agree   |
| 77 | I find crying helps me with stress  | 7.05,<br>p<.05    | 5.72<br>p<.02    | NS            | 5.35<br>p<.03 | Pall<br>agree   |
| 84 | I care for my body differently since working with patients who are seriously ill or dying | 10.02,<br>p<.01   | 9.91<br>p<.01    | 4.53<br>p<.05 | NS            | Psy<br>disagree |
| 85 | I find this work experience makes me 'live for the day'                                   | 10.05,<br>p<.01   | 9.99<br>p<.01    | NS            | NS            | Pall<br>agree   |
| 86 | I find this work experience makes me be more positive and outgoing                        | 8.53,<br>p<.02    | 7.72<br>p<.01    | 4.37<br>p<.05 | NS            | Psy<br>disagree |
| 87 | I find I make more short term goals   | 6.80,<br>p<.05    | 6.77<br>p<.01    | NS            | NS            | Pall<br>agree   |
| 88 | The rewards of my job outweigh the disadvantages  | 11.11,<br>p<.01   | 11.17<br>p<.001  | NS            | 7.57<br>p<.01 | Pall<br>agree   |

Notes: respondents were asked to agree or disagree with the above statements. The table gives Chi-Square statistics for test across three groups and the statistics for 2X2 crosstabs across the paired groups to determine where the significant difference appeared. The final column indicates which group demonstrated the strongest agreement or disagreement.

## **APPENDIX XI - Accumulated Loss Phenomenon vs Burnout (7.2.3)**

In the Maslach Burnout Inventory (MBI), Emotional Exhaustion refers to feelings of being emotionally exhausted and depleted of one's emotional resources (Maslach, 1993, p 20-21). Items on the MBI scale which are used to measure this element are:

- 1 I feel emotionally drained from my work
- 2 I feel used up at the end of the workday
- 3 I feel fatigued when I get up in the morning and have to face another day on the job
- 6 Working with people all day is really a strain
- 8 I feel burned out from my work
- 13 I feel frustrated by my job
- 14 I feel I'm working too hard on my job
- 16 Working with people directly puts too much stress on me
- 20 I feel like I'm at the end of my rope

Items on the Accumulated Loss Phenomenon (ALP) scale which, at face value, in a nursing context, could be seen either as symptoms of, or, consequences of, suffering from emotional exhaustion, (ALPEE) are:

- 10 I am stressed because I expect too much of myself
- 11 I am bothered by feelings of inadequacy
- 19 I expect more support than I get from members of other disciplines
- 23 I feel impatient with over-grieving families.
- 24 I find myself steering conversations with patients/families to stay on superficial topics
- 25 I avoid approaching tearful or emotional families
- 26 I am uncomfortable with hostility in patients/families
- 27 The dying patient who talks about his/her death is difficult to care for
- 32 I would rather care for an unresponsive patient who is dying than one who is conscious
- 37 I dread admissions for fear of bonding with them
- 38 I dread admissions because of lack of closure with a previous patient

continued .....

- 39 When working with another nurse I am less involved in the patient's care
- 40 There are times when I need another nurse with me, for help with physical or emotional issues
- 45 I feel overwhelmed by patient/family needs
- 46 I avoid passing the bed of a very needy patient/family
- 47 I am bothered by the lack of time to grieve after a patient's death
- 49 I dream about patients and their families
- 50 I dream about work situations
- 54 I avoid staff meetings where stress will be discussed
- 55 I attend fewer wakes or funerals outside work now
- 56 I dread going to bereavement functions
- 57 I call in sick when stressed or fed up
- 59 I have difficulty in letting go of events at work and getting involved in something after work
- 60 I find my work interferes with my relationships with others
- 68 I dread investing in new staff for fear of losing them
- 69 I feel loss of staff as much as death of a patient
- 78 Smaller losses take on more significance now
- 79 I have a sense of carrying a burden of accumulated losses at work
- 91 I am uncomfortable with the anger of others

Depersonalization is said by Maslach (1993) to be a negative, callous or excessively detached response to other people who are usually the recipients of one's service care. In the ALP scale there are several items which again, at face value, could be said to bear some relation to the concept of depersonalization. In the MBI, items which are used to measure this element are:

- 5 I feel I treat some recipients as if they were impersonal objects
- 10 I've become more callous toward people since I took this job
- 11 I worry this job is hardening me emotionally
- 15 I don't really care what happens to some recipients
- 22 I feel recipients blame me for some of their problems

continued...

Related items from the ALP scale (ALPDP) are:

- 14 I've become desensitized to death
- 22 I am troubled by my personal dislike of some patients/families
- 23 I feel impatient with over-grieving families
- 24 I find myself steering conversations with patients/families to stay on superficial topics
- 25 I avoid approaching tearful or emotional families
- 43 I get to the point where many patients look alike to me
- 46 I avoid passing the bed of a very needy patient/families

Reduced Personal Accomplishment, which is the third element in the MBI is defined as referring to a decline in one's feelings of competence and successful achievement in one's work. Items used to measure this are :

- 4 I can easily understand how my recipients feel about things
- 7 I deal very effectively with the problems of my recipients
- 9 I feel I'm positively influencing other people's lives through my work
- 12 I feel very energetic
- 17 I can easily create a relaxed atmosphere with my recipients
- 18 I feel exhilarated after working closely with my recipients
- 19 I have accomplished many worthwhile things in this job
- 21 In my work, I deal with emotional problems very calmly

ALP items which were totalled and correlated with this element (ALPPA) are:

- 10 I am stressed because I expect too much from myself
- 11 I am bothered by my feelings of inadequacy
- 12 I struggle with the conflicts between ideals and reality, theory and practice
- 13 I feel guilty when my daily work ideals are not achieved
- 58 I feel I am not keeping up with medical advances