

**Responses of Paraprofessional Nursing Staff  
to Death in Long Term Care**

**by  
Nicole Tupper**

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This thesis is dedicated to my husband, Don, and my daughters, Darienne and Lindsay

# TABLE OF CONTENTS

	PAGE
TABLE OF CONTENTS	v
LIST OF TABLES	viii
ABSTRACT	ix
ACKNOWLEDGEMENTS	x
CHAPTER I: INTRODUCTION	1
Background of the Study	1
Purpose / Objectives	2
Definition of Terms	3
CHAPTER II: LITERATURE REVIEW	4
Historical Perspectives	5
Death Anxiety in Nurses	6
Differences by Clinical Areas	8
Differences by Education / Experience	9
Nursing Behaviors	10
Attitudes Toward the Elderly	13
Reactions of Caregivers	14
Stress	16
Coping With Stress	19
Helping Nurses Cope	19
Summary of Literature Review	21

Research Questions	23
<b>CHAPTER III: METHODOLOGY</b>	<b>24</b>
Design	24
Population / Setting / Sample	26
Reliability and Validity of the Research Tool	27
Ethical Considerations	29
Data Analysis	30
<b>CHAPTER IV: RESULTS</b>	<b>33</b>
Description of the Sample	33
Personal Experiences	36
Work Experiences	37
Responses	39
Coping	41
Summary	42
<b>CHAPTER V: DISCUSSION OF RESULTS</b>	<b>44</b>
Demographics	44
Personal Experiences	45
Work Experiences	46
Emotional and Physical Responses	49
Coping	50
Assistance With Coping	51
Discussion of Methodology	52

<b>CHAPTER VI: SUMMARY AND RECOMMENDATIONS</b>	<b>54</b>
Limitations of the Study	54
Implications for Nursing Practice	55
Implications for Nursing Education	57
Implications for Nursing Research	58
<b>APPENDICES</b>	
A: Letter to Research Review Committee	60
B: Letter to Proposed Participants	61
C: Questionnaire	62
D: Most Difficult Death or Dying Situation Reported by PCW Staff	66
E: Types of Dying Residents Difficult to Care for as Described by PCW Staff	67
F: Difficult Issues Faced by PCW's Dealing With Death at Work	68
G: Physical Responses Reported by PCW's Dealing With Death and Dying	69
H: Emotional Responses Reported by PCW's Dealing With Death and Dying	70
I: Education Received by PCW's Related to Death and Dying	71
J: Coping Currently Used by PCW's and Strategies Suggested as Useful by PCW's	72
K: Sources of Support for PCW's Dealing With Death and Dying	73
<b>REFERENCES</b>	<b>74</b>

## LIST OF TABLES

TABLE		PAGE
1	Demographic Characteristics of Respondents	34
2	PCW Reported Means of Providing Privacy for Dying Residents and Their Families	40

## ABSTRACT

Personal Care Workers deal with death in long term care on a regular basis. There is little research completed involving this group of individuals and their responses to death.

Questionnaires were distributed to 110 Personal Care Workers at four long term care facilities within the same corporation. The questionnaire examined areas such as demographic data, personal and work experiences with death, difficult issues related to death at work, responses to death and coping strategies used.

A total of 29 Personal Care Workers participated in the study. The type of personal and work experiences caring for dying residents varied significantly. Physical responses reported included feeling exhausted, loss of appetite, headaches and nausea. A number of emotional responses were reported as well. These included feelings of sadness, loss, peace and increased concern for others. The paraprofessional nursing staff responses were similar to responses of professional nursing staff in the literature.

Coping strategies most commonly used by the PCWs in the study were talking to coworkers, moving on with their lives and praying. Some respondents offered suggestions for strategies which they felt could assist PCWs in dealing with death.

Data analysis was completed using a content analysis approach. The results were presented using some of the respondents own words, tables and charts.

Implications for education, practice and research were identified. Paraprofessional staff in the facilities studied indicated the need for formalized support systems to assist in them in the grieving process. Feelings of guilt at the limited time available to spend with the dying residents was clearly a concern for the respondents.

The need for educational programs tailored to the staff within each facility was also apparent. Further research in this area is needed to support and assist paraprofessional staff working in long term care to effectively manage caring for the dying resident.



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## CHAPTER I

### Introduction

#### Background of the Study

Research has suggested that professional caregivers experience grief at the loss of a patient (Fulton, 1987; Robbins et. al.; 1992, Saunders & Valente, 1994; Stowers, 1983.). Staff can experience psychological, physiological or behavioral grief reactions.

Numerous studies related to quality of life issues for terminally ill individuals can be found in the literature (Berardo, 1992; Cella, 1992; Coates, 1992; Cohen & Mount, 1992; Courtens et. al., 1996; Dudgen, 1992; Dush, 1993; Gaston et. al., 1996). There is also abundant literature related to hospice or palliative care (Burge, 1993; Glass, 1993; Gurfolino & Dumas, 1994; Knowles, 1993; McWilliam, 1993; Rose, 1995). However, there is very little literature available which describes the responses of paraprofessional staff to death in long term care settings.

Death is a frequent occurrence in nursing homes for elderly people (Robbins et. al., 1992). Homes are frequently under-staffed, and in many cases, there may be only one registered nurse on duty at any one time who has the responsibility of supervision and support of those paraprofessional staff providing the direct resident care (Robbins et. al., 1992). A gap exists in the knowledge base involving paraprofessional nursing staff responses to death. In

order to more effectively assist these individuals to cope with caring for the terminally ill resident, research is needed.

This exploratory and descriptive study describes paraprofessional nursing staff responses to death in a Home for Special Care. It will assist nursing administrators to identify common responses to death in long term care settings while providing directions for future education and research. The ultimate benefits will be for the caregivers and subsequently improve the quality of care provided to the residents.

#### Purpose/ Objectives

The purpose of this study is to explore and describe the responses of paraprofessional nursing staff to death in a Home for Special Care. The objectives of the study are:

1. To seek information from paraprofessional nursing staff regarding their personal and professional death experiences;
2. To determine coping strategies currently used by those individuals;
3. To identify potentially helpful coping strategies for paraprofessional staff in long term care settings.

### Definition of Terms

For the purpose of this study, several terms have been defined. The following list clearly identifies the researcher's understanding of the terms used in the study.

*Paraprofessional Nursing Staff.* Any non-registered staff person employed in a long term care facility who provides personal care to the residents. Common job titles for these individuals include Personal Care Worker (PCW), Nurse's Aide (NA) or Health Care Worker (HCW).

*Responses:* Responses will be subjectively determined and may constitute any reported physical, spiritual, social or behavioral reactions to death.

*Death:* The cessation of life; ceasing to exist; defined by physicians as a total stoppage of the circulation of blood, and a cessation of the animal and vital functions consequent thereon, such as respiration, pulsation, etc. (Cowles, 1984, p.169).

## CHAPTER II

### Literature Review

A computerized literature search was conducted using the following databases: Psychlit, Medline, Sociofiles and CINAHL (Cumulative Index of Nursing and Allied Health Literature). The initial searches focused on paraprofessional nursing staff and death in long term care. There is very limited research involving paraprofessional nursing staff and none which specifically examines responses to death in this population. It was felt that reviewing research involving professional nursing staff would assist the researcher in developing the study and to gain a broader knowledge base by examining literature involving a related group of individuals. A variety of topics related to death and dying were searched including death anxiety in nurses, nurses responses to death, attitudes toward the elderly, responses of caregivers to death, stress in nursing, and death in long term care. Based on the findings in these general categories, specific searches were completed. The areas of bereavement, grief and family responses were also explored. A manual search was also completed to ensure that no other appropriate topics were missed. The pertinent information related to responses of paraprofessional nurses to death in long term care is now outlined under the headings of historical perspectives, death anxiety in nurses, differences by clinical areas, differences by education / experience, nursing behaviors, attitudes toward the elderly, reactions of caregivers, stress, coping with stress, and helping nurses cope.

## Historical Perspectives

The beginnings of death related research are seen in the field of anthropology as early as 1915 (Benoliel, 1983). Research was not limited to anthropology however, in psychology, such ideas as Freud's concepts of unconscious immortality and death instinct were available (Benoliel, 1983).

After World War II there was an increased interest in death related research. Benoliel (1978) argues that this was due to :

the rapid expansion of organized science, the mental health movement's interest in death, depersonalization of many human experiences associated with technological development and a pervasive death anxiety coming in the aftermath of Hiroshima (p. 9).

Between 1940 and 1960 there was increased research in the fields of psychiatry, sociology, and psychology. In 1959, Fiefel began his now famous work on attitudes toward death. He was also involved in the amalgamation of a number of essays on the meaning of death.

Fulton (1961), Glaser and Strauss (1965, 1968), Sudnow (1967) and Kubler-Ross (1969) made significant contributions to knowledge about personal, interpersonal, and social aspects of death and dying. Five stages of death and dying are identified by Kubler-Ross (1969). Denial and isolation, anger, bargaining, depression and acceptance are listed as the stages of dealing with death and dying. This research has enlightened health care professionals about the complex processes of preparing for death.

Nursing research on topics related to death began in the 1960's. Quint (1967) described the tasks involved in caring for the dying patient. She also identified, at that time, many of the difficulties that nurses, nursing students and nursing faculty face when dealing with the terminally ill especially communicating with the dying patient (Quint, 1966,1967; Quint & Strauss, 1964). These topics have been studied over the past decade (Coty, Downe-Wamboldt, & Tamlyn, 1982; Degner & Gow, 1993; Krisjansen, 1993).

Degner and Gow (1988) completed a longitudinal study comparing undergraduate nursing students who had received a course in palliative care to a group of students who did not participate in the course. One year post graduation, the students who had participated in the course had an improved approach to care with terminally ill residents.

### Death Anxiety in Nurses

Folta (1965) utilized a perceived dimensions measure, anxiety scale and a sacred-secular scale to determine nurses' perceptions of death. The highest proportion of nursing personnel viewed death as a natural and positive phenomenon yet they still experienced "death anxiety". Staff nurses experience the highest level of anxiety followed by practical nurses, nurses in administration, and attendants.

Similar findings were reported by Gow and Williams (1977) who explored death anxiety in nurses and discovered that an individual's age rather than their

position impacted on their death anxiety. Younger nurses had more negative attitudes than older nurses. The medical population is no more anxious, and perhaps less so, than non-medical populations about death (Folta, 1965). Nurses rank in the “low fear of death” group as compared to the general population.

Death anxiety has been studied in nursing and medical students to determine if relationships among communication apprehension with the dying and empathy exist. The study involved groups of freshman and senior nursing and medical students. The results indicate positive correlations between death anxiety and communication apprehension with the dying and death anxiety and empathy. A third positive correlation identified by the researchers was obtained between empathy and sex. Females scored higher on the empathy scales than males. The findings also suggested that seniors are less apprehensive than freshman about communication with the dying. The length of education, number of life experiences, age, and maturity of these individuals may all play an influencing role (Severty, Krejci, & Hayslip, 1996).

Peace and Vincent (1988) compared death anxiety in relation to education among hospice care nurses and non-hospice nurses. Templer’s Death Anxiety Scale was used in conjunction with a questionnaire developed by the researchers to collect the data. The findings of the study indicate that there are no significant differences in death anxiety between the two groups. However, the nurses’ educational preparation in caring for the dying varied



significantly. Generalizations regarding the findings in this study should be viewed in the context of the limitations.

### Differences by Clinical Area

Golub and Reznikoff, (1971) and Lester et al., (1974), found no significant differences in death anxiety levels in graduate nurses working in different clinical areas. Conversely, Thompson (1985-86), in a study of curative and palliative care nurses, discovered that pediatric nurses are significantly less anxious about death than surgical or palliative care nurses. However, he also noted that palliative care nurses are less likely to feel uneasy caring for the dying patient and are more likely to feel useful. He attempted to account for age and experience as variables but felt overall that "experience itself is not as significant as the setting in which the nurses work" (p. 240).

Glaser and Strauss (1965) suggest that :

Different work situations and nursing units are characterized by different task structures and mortality rates. Each unit approaches its work with the dying with its own philosophy, where the emotional climate in a unit encourages a particular affective reaction to death (p. 95).

Vincent and Garrison-Peace (1986) administered the Personal Orientation Inventory to two groups of nurses: 39 hospice nurses and 429 nurses from "traditional clinical settings". Their study revealed that hospice nurses had greater self-confidence, self reliance and maturity than non-hospice nurses. Hospice nurses also had stronger beliefs in life after death, stronger feelings of satisfaction with life, and greater satisfaction with their work.

Nurses view death more positively than do physicians (Campbell, Abernathy & Watehouse, 1983-84). Perhaps this is due to the sense of failure felt by a physician when a patient dies. Student nurses are more likely to favor "all possible efforts" to save life where a registered nurse may see the "inevitability and appropriateness of death in some circumstances" (Campbell et. al., 1983-84, p. 506).

### Differences by Education / Experience

In a study of undergraduate nursing students, graduate nursing students, and nursing faculty, it was found that fear of death and dying decreases as academic preparation increases with one exception; first year graduate students scored higher in fear of death than senior undergraduate students. The suggested explanation was that the level of experience would skew these results (Lester et al., 1974). Other research conducted in the 1970's supports these results (Golub & Reznikoff, 1977; Hopping, 1977)

More recently, a meta-analytic procedure was used to review 47 studies related to the impact of death education programs. Durlak and Riesenber (1991) concluded that "death education programs have been more successful in changing participants' attitudes on death related issues than in changing their personal feelings about death" (p. 49). The type of program was also considered to be a variable impacting on the outcome of the education program.

Work experience has also been noted to affect an individual's anxiety level in relation to death. Experienced nurses have a higher level of anxiety than students with little or no experience. Thus, experience is inversely related to anxiety (Denton & Wisenbaker, 1977). This finding has been supported by Murphy (1986).

The purpose of the study was to evaluate the effectiveness of a two day workshop in reducing death anxiety. A group of nurses who attended the workshop and a control group of nurses who did not attend the workshop completed questionnaires on three separate occasions. A pre-test, post-test on completion of the workshop and a post-test one month later were completed. The results indicated that nurses who attended the workshop had a significantly lower level of death anxiety between the pre-test and the two post-tests following the workshop as compared to the control group who had no significant differences in results. This study also indicated that the age of the subjects and their length of work experience had an impact on their death anxiety. Those nurses who were in their thirties and had worked seven to twelve years showed the greatest decreases in death anxiety (Murphy, 1986).

### Nursing Behaviors

Degner, Gow and Thompson (1991) undertook a research project to identify "critical nursing behaviors in care for the dying". In this study, nurse educators and experienced palliative care nurses were asked to describe

situations where nursing students displayed either positive or negative behaviors when caring for the dying.

Both positive and negative behaviors were identified in the following areas:

Behaviors	Positive Responses	Negative Responses
Responding during the death scene	Behavior that maintains a sense of calm	Behavior that shows the nurse's horror of the scene
Providing comfort	Behavior that reduces physical discomfort	Controlling behavior that eliminates the family
Responding to anger	Behavior showing respect and empathy even when anger is directed to the nurse	Avoidance behavior or angry response
Enhancing personal growth	Behavior showing the nurses personal role in caring for the dying	Behavior showing anxiety or lack of confidence in caring for the dying
Responding to colleagues	Behaviors that provide emotional support and critical feedback to colleagues	Behaviors that show difficulty in providing support or receiving criticism from colleagues
Enhancing the quality of life during dying	Behaviors that help patients do things that are important to them	Behaviors that show lack of respect for the resident or family
Responding to the family	Behaviors that respond to the family's need for education	Ignoring the family's need for information

(Degner et. al., 1991)

This study was limited in that only two groups of nurses were included.

However, it clearly indicated that avoidance behaviors continue to be

demonstrated by individuals who care for the dying (Degner et. al., 1991).

Skorpuka and Bohnet (1982) approached the topic of nursing behaviors in a slightly different manner. Q- Sort methodology was used to identify nursing behaviors deemed most helpful to primary caregivers. Caregivers reported that nursing behaviors related to the patient's physical and emotional needs were the most helpful.

Several researchers have identified nurses responses in dealing with death (Alexander, 1990; Feldstein & Gemma, 1995; Saunders & Valente, 1994; Sumaya-Smith, 1995). In a study of 300 oncology and hospice nurses, Saunders and Valente (1994) found that nurses feel they have managed their grief at the loss of a patient effectively if they helped the patient die a "good death". The following conditions were described as contributing to a "good death":

- a) The nurse had relieved the patient's distress and symptoms to the extent allowed by current knowledge and technology;
- b) Patients had a chance to complete tasks related to their important relationships;
- c) The nurse believed that he or she had delivered the best quality of care possible for the patient;
- d) The person's death did not violate the natural order;
- e) The patient's death was contextually appropriate. (Saunders & Valente, 1994, p. 320).

### Attitudes Toward the Elderly

Numerous studies have demonstrated the existence of both death anxiety and negative attitudes toward the elderly among nurses and physicians (Campbell et. al., 1983-84; DePaola et. al., 1992; Feifel, 1959; Gillis, 1973; Thompson, 1985-86). Work experience in a nursing home has been shown to increase staff avoidance of death and dying (Howard, 1974; Pearlman, 1969). However, there is limited research available which focuses on paraprofessional nursing home staff and their involvement with the elderly.

A few studies have examined the attitudes held by different levels of nursing home staff, -RN's, LPNs and NAs- toward elderly patients (Chandler, Rachel & Kazelskis, 1986; Smith et. al., 1982; Taylor & Harned, 1978). Smith, Jepson and Perloff (1982) found that the attitudes of different nursing personnel toward the elderly differed according to their level of training. RNs have more positive attitudes toward the elderly than do LPNs or NAs.

Robbins et. al. (1992), in a study of care assistants in nursing homes, examined the relationship between death anxiety, the anxiety dealing with the practicality of dealing with death, and the level of experience of care attendants. The results indicate that age was the best predictor of both death anxiety and practical anxiety, the two being inversely correlated.

It has been suggested that attitudes toward the elderly will affect the quality of care in the nursing home (Burnside, 1994; Miller, 1976). Eakes (1985) confirms the existence of negative attitudes toward the elderly among nursing

home staff members. He also discovered that staff with high death anxiety had more negative attitudes toward the elderly. Some researchers have suggested that negative attitudes toward the elderly may be mediated by a caregiver's own death anxiety ( Eakes, 1985; Lester, Getty & Kneisel, 1974).

### Reactions of Caregivers

Abundant literature exists which describes the many emotional problems facing caregivers who work with dying patients (Koocher, 1979; Rando, 1984; Strauss, 1968). If the caregiver views death as an obstacle to be overcome, then feelings of powerlessness and failure may result (LeShan, 1969; Menzies , 1960). Dealing with dying patients may result in thoughts of one's own death or the death of loved ones.

Feelings of sadness, crying, anger and anxiety have been identified as emotions linked with grief. Disruptions in sleep patterns, appetite, interest, concentration and social functioning may also be present when an individual is experiencing grief. Nurses may hesitate to cry in front of family members due to professional standards. Conflict occurs between personal feelings of wanting to cry and professional feelings to stifle the tears. This may lead to nurses concealing their anxieties about a patient's death from themselves and their peers (Saunders & Valente, 1994).

In a study by Alexander (1990), 38 palliative care nurses completed questionnaires and were interviewed to identify sources of stress and how they

deal with them. Personal experiences of working with dying patients was identified as the most influential factor in shaping nurses' attitudes towards death. The following patient symptoms and behavior were identified as causing the most stress for nurses:

- Dealing with intractable pain;
- Dealing with young children;
- Dealing with patients who are afraid to die;
- Dealing with patients who do not accept their illness ( Alexander, 1990).

Robbins et al. (1992) noted that nursing home staff also have to face the task of coping with their own attitudes to aging and death. In addition to providing care for residents, these staff frequently form strong interpersonal relationships as a result of the long-term exposure to their care. Saunders and Valente (1994) reported that the closeness of a relationship influences how nurses respond to death.

Hare and Pratt (1989) compared the reactions of professional nurses to paraprofessional nurses. They discovered that professional nurses were more comfortable dealing with patients who have a poor prognosis for survival. This difference in comfort level may be especially important as 94% of the paraprofessional population in this study worked in nursing homes. The difference in comfort level may be attributed to differences in staffing levels as nursing homes have larger complements of paraprofessional staff ( Hare & Pratt, 1989).



Paraprofessional nurses deliver most of the care to the nursing home resident, yet, they have limited training in dealing with both the physical and psychological needs of patients (Sumaya-Smith, 1995). Although many nursing homes use work teams, paraprofessional staff in nursing homes provide the majority of the care. Furthermore, the typical nursing home patient suffers from multiple chronic illnesses; thus more extensive nursing care is required. The paraprofessional staff are overextended and less comfortable dealing with the dying patient than are professional nurses (Hare & Pratt, 1989).

### Stress

One source of stress for the nurse in caring for the terminally ill patient relates to a medical orientation that emphasizes cure. Once a patient has been diagnosed as terminally ill, the nursing focus should shift from cure to care. This has been identified as a source of conflict by many researchers (Baider & Porath, 1981; Bonine, 1967; Mandel, 1981; Reisetter & Thomas, 1986; Thompson 1985-86).

Strank (1972) questioned nurses in a variety of settings to identify causes of stress when caring for the terminally ill. Several items were identified and the question "Is this stress?" was asked for all items. The overwhelming response was affirmative. The nurses identified stress borne with the age of the patient (the younger, the more stressful), alteration in the resident's appearance due to treatments, and whether the patient and relatives had not been told of the poor

prognosis. Coping with an unanticipated and/or sudden death also increases a nurses stress level (Valente & Saunders, 1988).

Nurses are particularly vulnerable to the deaths of patients whom they like, have known for long periods of time, whose death carries high social loss, and with whom there is involvement with the family (Quint, 1966). The type, quality, closeness, intensity, and the importance of the relationship will also influence how nurses respond to death (Saunders & Valente, 1994).

Glaser and Strauss (1965) assume that the death of an elderly person, except in unusual circumstances, would be viewed as entailing less social loss than the death of a middle - aged adult or a child. Support for this observation can also be found in Saunders and Valente (1994).

Factors influencing bereavement in nurses have been recently identified as well (Alexander, 1990; Feldstein & Gemma, 1995; Saunders & Valente, 1994; Stowers, 1983; Sumaya - Smith, 1995). Developmental age of the nurse influences how one grieves and copes with death. It is suggested that the more mature the developmental age, the more flexible the person's coping strategies (Saunders & Valente, 1994).

Stowers (1983) believes that nurses are seldom able to share the grief they feel at the loss of a patient. Nurses describe being "too busy" to show the grief they are experiencing or feeling afraid to show their feelings. Thus, they face the loss in their own way without sharing feelings or comfort and sometimes

this results in a grief reaction manifesting itself after another experience with death.

Dealing with the dying patient has posed a major problem for many nurses. They feel ill equipped by both their formal and informal education to deal with unstructured conversations (Kubler- Ross, 1969; Quint, 1973). The obvious discomfort that nurses feel when dealing with patients with emotional needs has been documented as well (Keck & Walter, 1977). Stoller (1980) felt that this discomfort could be due to "normative ambiguity" and the uncertainty of how to act.

Stress is manifested by nurses in a number of ways. Mandel (1981) suggests being sick, tired, and voicing grievances are often symptoms of stress. A study was carried out to determine issues faced by nurses who deal with dying patients. Anger directed at oneself and guilt about acting unprofessionally were the most often cited concerns. Anxiety, lack of skills and power, a sense of being overwhelmed, overidentification with the patient, depression, sadness, avoidance in forming close ties, and confusion over roles were all identified by nurses as issues causing stress in caring for the terminally ill (Mandel, 1981).

Robbins et al. (1992), in a study of nursing home staff, found that staff are "expected to cope using the traditional methods of stoicism and denial of feelings" (p.550). Others ( Hare & Pratt, 1989; Lavigne-Pley & Levesque, 1992; Sumaya - Smith, 1995) have also found that this is a frequent occurrence in nursing homes as "institutions try to make death invisible" (Sumaya - Smith,

1995, p.450). This approach may lead to increased stress for some of the nursing staff working in those environments.

### Coping With Stress

Numerous researchers have examined nurses' coping abilities with the stress accompanying care for the terminally ill. Usually unstructured interactions with the patient cause the most anxiety (Campbell et. al., 1983-84; Mood & Lakin, 1979; Mood & Lick, 1979; Quint, 1966).

Stoller(1980), identified coping strategies commonly used by nurses to deal with the anxiety. Minimizing the amount of time spent with the patient, maintaining social distance, and controlling the context of the conversation are frequently used. Support for these findings is found throughout the literature (Glaser & Strauss, 1965; Kubler-Ross, 1969; Quint, 1966).

Composure strategies used by nurses were described by Quint (1966). The nurse maintains a professional demeanor exuding a "busy air" which signals to the patient that they have no time for questions. Verbal cues from the patient are ignored and the nurse may employ selective listening or avoid talk of the future.

### Helping Nurses Cope

Researchers have suggested that nurses need a place away from the ward to vent their emotions and express thoughts with other professionals.

Open ward meetings and peer counseling could be useful in helping nurses cope with caring for the dying (Mandel, 1981; Nutall, 1977; Sheard, 1984).

Sheard (1984) suggests that a post-mortem conference two or three days following a death would be helpful to nurses in venting their emotions. Allowing the bed to remain empty for twenty-four hours encourages an expression of loss. Attendance at the funeral, photographs of the patient, and family follow-up are also means used to help nurses cope.

Sumaya-Smith (1995) suggests that "nontraditional methods" could encourage the grief process and thus assist the caregiver in coping with death. She suggests that caregivers be allowed to talk about the death with other caregivers or surviving residents.

The nursing situation is appropriately summarized as :

The stark reality that nurses encounter when working with terminal patients requires a total re-evaluation of their task, geared not to curing but rather to improve care, training, supervision and group or individual support must provide them with feedback and stimulation necessary to appreciate and go on with the unique and valuable work (Baider & Porath, 1981, p. 52)

Nurses often have a closer relationship with the terminally ill than other staff because they are usually with such patients long enough to establish a relationship (Garfield, 1965). How nurses perceive the act of dying - as painful, as upsetting, with indifference, as a blessing, and so forth- influences the treatment that they give a dying patient during his / her last days in the hospital or nursing home. Nurses have the potential to enhance the understanding of

death with patients or to create even more problems for patients and their understanding of their changing physical state (Mullins & Merriam, 1983).

### Summary of Literature Review

Much of the literature reviewed for this study has examined professional nursing staff responses to caring for the terminally ill resident. There is no question that caring for the dying has an important impact on individuals.

Death anxiety in nurses has been examined by a number of researchers. Overall, the suggestion is that nursing staff view death more positively than do medical staff and the general population.

When clinical areas are examined as a variable affecting death anxiety, there are discrepancies in reported results. Golub and Reznikoff (1971) and Lester et. al (1974) found no differences in death anxiety by clinical area. However, Thompson (1985-86), describes differences noted with pediatric, surgical and palliative care nurses.

Level of education of professional nursing staff and nursing students has also been compared in the literature. Generally the results indicate that as education level increases, death anxiety decreases. Thus, paraprofessional staff should experience higher levels of death anxiety than professional staff due to the limited training of the paraprofessionals. The effects of workshops as training for staff has also been evaluated. Again, as the amount of education

increases, death anxiety decreases. Some variables like the age of respondents and the level of experience have been identified as contributing to the change.

Nursing behaviors in palliative care were examined in the literature. Critical nursing behaviors in caring for the dying have been identified as well as physical and emotional responses to caring for the terminally ill. These studies focused on stress and caring for the dying in the professional nursing staff population.

Some researchers who have examined attitudes toward the elderly have discovered that attitudes vary according to the level of training. Robbins et. al (1992), suggest that the age of the participants was the best predictor of death anxiety.

Some researchers have attempted to identify helpful coping strategies for nurses who care for dying residents (Mandel, 1981; Sheard, 1984; Stoller, 1980; Sumaya-Smith, 1995). Open ward meetings, peer counseling, and attendance at funerals were just a few of the suggested strategies.

The literature reviewed points out gaps in research especially related to paraprofessional nursing staff responses to death in long term care centers. Some similarities may exist in the responses of paraprofessional staff as compared to professional staff and this area needs to be examined. Since paraprofessional staff are highly involved in palliative care, they are likely to experience stress in caring for dying residents. It is important to identify current coping strategies and potentially helpful strategies.

## Research Questions

This study addressed the following questions:

1. How do personal care workers in long term care describe their personal and work experiences with the dying?
2. What coping strategies are currently being used by personal care workers to assist them in dealing with death?
3. What are some potentially useful coping strategies dealing with death and dying identified by personal care workers in Homes for Special Care?



## CHAPTER III

### Methodology

#### Design

An exploratory, descriptive design was selected as most appropriate for the study as little research is available concerning responses of paraprofessional nursing staff to death. The study took place in Atlantic Canada, in four large nursing homes, with a total of 840 beds. Permission was obtained from the Human Ethics Review Committee of the University as well as the Administration and Research Review Committee of each institution prior to the initiation of the research (Appendix A).

A list of all personal care workers employed in each facility was obtained from the payroll clerk. A sequential number was assigned to each name on the list and a table of random numbers was used to assist the researcher in determining which individuals would be invited to participate in the study.

An introductory letter and a copy of the questionnaire was sent to individuals outlining the study and requesting their participation. The date of a group meeting for each facility was also forwarded to each prospective participant at that time. (Appendix B). Two weeks following the group meetings a reminder memo was sent to each Nursing Home and was posted in a visible location to remind individuals to complete the questionnaire.

The subjects were invited to attend one of several group sessions facilitated by a Master in Health Administration Student who had no direct

relationship to the nursing home. This person was not associated with the employees nor was she known to the employees. She received an orientation to the questionnaire and the study from the researcher prior to the first group meeting. The group sessions consisted of a brief introduction to the facilitator and the topic under study. The respondents were then given the option of completing the questionnaire during the group meeting and placing it in a sealed envelope or mailing the completed form directly to the researcher. They were also offered an opportunity to meet with the researcher if they wished to be interviewed.

The subjects were assured of the confidentiality of their responses and that their participation was voluntary. The data collection tool, Paraprofessional Nursing Staff Responses to Death in a Long Term Care Setting, was developed by the researcher and is composed of twenty-three items (Appendix C). The questions were developed from the literature which describes some of the responses of other groups of individuals who deal with death and dying on a regular basis. The grade level of the questionnaire was examined to determine the appropriateness of the level. The results indicated a Flesch- Kincaid grade level of 6.4 which would be appropriate for the sample. The questionnaire was pilot tested to determine the appropriateness of the questions.

The instrument is divided into two sections. The first section deals with demographic data about the respondents. Six questions cover the topics of age,

sex, religious affiliation, education level, length of employment and years of experience in caring for dying residents. The purpose of these questions was to obtain demographic information about the respondents.

Part Two consists of seventeen questions about the individual's experiences and responses to death including physical, emotional and behavioral components. Specific experiences in their personal lives as well as their work lives are explored. The final section of questions focuses on the coping strategies used to help individuals cope with death.

#### Population/ Setting/ Sample

A simple random sample of part-time and full-time paraprofessional staff was obtained from a convenience sample of four large nursing homes in Atlantic Canada. Each nursing home is accredited through the Canadian Council on Health Services Accreditation. Continuous quality improvement is a philosophy which is practiced in these homes. Staffing ratios vary in each home and on each unit based on the residents needs. Generally, a PCW would be responsible for 6-10 residents on any shift while the RN would be responsible for an entire unit, 41-56 residents.

In order to obtain a large population base for sampling, it was necessary to use four nursing homes. A list of all paraprofessional employees was obtained from each facility. Random numbering was used to determine which of

the 289 employees were approached for participation. All completed questionnaires are included in the data base.

Inclusion criteria for the subjects included:

- Employment as a personal care worker in the facility for a minimum period of three months,
- Willingness to participate in the study, and
- The ability to read, speak and write in English.
- Previous experience caring for the dying would be necessary for those individuals wishing to be interviewed.

A total of 100 individuals proportionally divided among the homes received a letter and a copy of the questionnaire from the researcher requesting their participation in the study (Appendix B). The questionnaires and letters were sealed in an envelope with the selected employees names written on the outside and those envelopes were placed with the employees time card. Initially, 100 individuals were approached as response rates with questionnaires may be as low as 25-30% ( Nieswiadomy, 1993). Brink and Wood (1994) suggest that at least 20 participants are required. Therefore, a 20% response rate would achieve the minimum number.

### Reliability and Validity of the Research Tool

Reliability of a research tool relates to the consistency, stability and repeatability of a data collection instrument (Brink & Wood, 1994) Validity of the instrument assesses whether or not it measures what it is supposed to ( Wilson, 1989). Content validity of the questionnaire is a self-evident measure which compares the content of the measurement technique to the known literature and validating the fact that the tool does reflect the literature accurately. It is estimated from the literature or through experts in the field (Brink & Wood, 1994). Instruments in a descriptive study design need to be tested for reliability and validity. A panel of three content/ practice experts who were members of the thesis advisory committee examined the face validity of the questions.

A pilot study is suggested to assess the strengths and the scope of the instrument (Brink & Wood, 1994). Therefore, a pilot study of 10 participants was undertaken in the fourth long term care facility owned by the same corporation. The results of the pilot study were examined to determine if the responses could be included in the data analysis. As only two minor revisions were deemed necessary, it was decided that the responses would be included in the study results.

The revisions in the questionnaire were indicated in questions 14 and 16. Question 14 was changed from "How do you deal with the privacy needs of the

dying resident and their family?” to “How do you provide for the privacy needs of the dying resident and their family?”. The second revision was in question 16. “What physical responses have you noticed after you cared for a dying resident?” was changed to “What physical responses have you noticed in yourself after you cared for a dying resident?”

### Ethical Considerations

Prior to the initiation of the study, review and approval by the Thesis Committee, the Ethics Committee of the Faculty of Graduate Studies and each facility was obtained. The rights of the participants were protected by ensuring informed consent was obtained and by maintaining their confidentiality. Consent was implied by the completion and submission of the questionnaire to the researcher. Participants were advised that they could withdraw from the study at any time without penalty. The administration of the home was not informed of who had or had not participated in the study nor was the researcher aware of who responded. Individuals were also given the option of mailing in their responses directly to the researcher.

The purpose of the study was explained to all respondents to ensure understanding of the study at its onset. The respondents were also informed that participation was voluntary and that their identities and responses would be kept

confidential. The respondents were also informed of their right to refrain from commenting on any item of their choosing.

### Data Analysis

Descriptive statistics were used in the analysis of the demographic variables. Graphs and tables are used to show the findings for

Recorded words and sentences are human artifacts that provide rich data about the personalities, thoughts and attitudes of their writers ( or speakers) as well as extensive information about their interpersonal, social, political and cultural contexts( Waltz, Strickland, & Lenz, 1991, pp. 299).

In order to obtain the richest possible information from the data collected, a content analysis approach was used to analyze the data. Nieswiadomy (1993) describes content analysis as “a data collection method that examines communication messages that are usually in written form” (pp. 373)..

Several steps have been identified in this process:

1. Defining the universe of the content to be analyzed;
2. Identifying the characteristics or concepts to be measured;
3. Selecting the unit of analysis to be employed;
4. Developing a scheme for categorizing the data;
5. Pretesting the categories; and
6. Performing the analysis. (Waltz, Strickland, & Lenz, 1991).

Critics of this type of research state that this method is prone to problems of reliability and validity (Woods & Catanzaro, 1988). The researcher has used consistency in identifying the units to be categorized and assigning the units to categories. The specific categories were gleaned from the information provided by the respondents. Upon completion of the pilot project, the researcher was able to develop a tentative list of categories which was refined once all respondents had completed the questionnaire.

The general headings of physical, mental, behavioral responses, and coping mechanisms can be found in the data collection tool. Individual experiences were examined as they appeared. Each category is clearly different from all other categories.

Talbot (1995) suggests that inter-rater reliability occurs when two or more trained raters are asked to independently rate the same object or event at the same time. The scores are then compared to obtain a percentage of agreement. The researcher uses a score of 70% or higher as a general guideline for the agreement score. Polit and Hungler (1995) suggest the following equation be used to determine the percentage of agreement:

$$\frac{\text{Number of agreements}}{\text{Number of agreements} + \text{disagreements}}$$

A random sample of all responses was selected by a second rater. The categorizations of the two raters were compared with the following results



$42/51 = 82\%$ . This number exceeds the suggested percentage of 70 thus the reliability of the coding was considered acceptable.

As well, intra-rater reliability was assessed by the researcher. On two separate occasions four weeks apart, the researcher examined the data and coded it into the identified categories, with the percent of agreement being 95. Thus the intra-rater reliability scores indicate the reliability of the response coding.

Validity as described by Brink and Wood (1994) is the extent to which the categories represent the theme or concept on which they are based. Through follow-up with willing participants, the researcher would have been able to validate if the coding of the data accurately reflected the intent of the participants. Unfortunately none of the respondents expressed interest in being interviewed. Face validity is apparent through the rationale for the categories and their definitions. Each category is shown to be appropriate to the data.

## CHAPTER IV

### Results

The results of the study are presented including a demographic description of the sample. The survey results are presented with tables, charts and narrative descriptions of responses to death from the completed questionnaires. There were no interviews completed as none of the respondents indicated an interest in meeting with the researcher. Personal and professional experiences with death are reported as well as the coping strategies used and potentially helpful strategies as identified by the respondents.

#### Description of the Sample

A total of 29 Personal Care Workers (PCW) responded to the questionnaire achieving a response rate of 26% despite reminders to complete and return the questionnaire. The mean age of the respondents was 38.2 years, with a range of 24 -57, and a standard deviation of 9.5. The sample consisted of 28 females and one male. In the population of all PCWs employed in the three nursing homes involved in the study, 8.7% were male, while only 3.4% of the respondents were male. (See Table 1)

All of the respondents had some high school education. Most of the respondents ( $n = 26$ ) had completed some additional training which ranged from a PCW course to some university education. Over half of the respondents (55%) have completed either a PCW or Certified Nursing Assistants course.

Table 1

## Demographic Characteristics of Respondents

Characteristics	n	%
<b>SEX</b>		
Female	28	96.5
Male	1	3.5
<b>RELIGIOUS AFFILIATION</b>		
Roman Catholic	14	48.4
Anglican	5	17.3
United Church of Canada	3	10.4
Baptist	2	6.9
Christian	1	3.4
Nazarene	1	3.4
Protestant	1	3.4
Orthodox Christian	1	3.4
None	1	3.4
<b>EDUCATION LEVEL</b>		
High School (Grade 9 - 12)	3	10.3
Some Community College	1	3.4
PCW Course	13	44.8
CNA Course	3	10.4
Some University	9	31.0
<b>LENGTH OF EMPLOYMENT</b>		
Less than 1 year	2	6.9
1 - 5 years	5	17.3
6 - 10 years	9	31.0
Greater than 10	13	44.8
<b>YEARS OF EXPERIENCE</b>		
Less than 10	11	37.9
11- 20	13	44.8
21 or more	5	17.3

All respondents have worked in a nursing home for a minimum of three months. Almost half of the individuals have been employed for greater than 10 years ( $n = 13$ ). As length of employment within nursing homes increases, one may reasonably expect that exposure to death or caring for dying residents also increases.

In addition to the years of employment in a nursing home, the number of years caring for dying residents was examined. There were five individuals with 21 or more years experience in caring for the dying. Of the remaining individuals, 11 had less than 10 years experience, while 13 had 11-20 years experience in working with the dying. The actual number of encounters with dying residents was not collected.

Personal experiences with death varied greatly. Experiences with deaths in both the immediate family and extended family and friends was the most common ( $n = 10$ ). Three individuals reported no personal experiences with death. The remaining individuals had experienced deaths either within their immediate or extended families.

In examining work experiences with the dying, 23 respondents reported working with dying residents within the last six months. Only three individuals had experiences greater than 12 months ago. When one considers the environment of a nursing home and the average age of the residents, it is not surprising that death experiences would be recent.

## Personal Experiences

The number and type of personal experiences with death varied greatly. Providing support for other family members, assuming a caregiver role for survivors, being present at the time of the death, and remaining with a loved one through the hospitalization period were the most often cited experiences. Some individuals have experienced several deaths within a six month period, others have never dealt with death in their personal lives. One individual described a poignant situation on her questionnaire: "The man I adored most in the world recently died. I have never felt such immense sadness. The death of my father has left a hole in my heart that I will take to my grave."

The most common situation encountered by the respondents was dealing with emotional responses ( $n = 11$ ) in themselves or others. Loneliness, depression, feelings of loss and emotional turmoil are the most common responses noted in dealing with death in their personal lives. The literature suggests that all of the aforementioned responses are common grief reactions and therefore would be expected responses (Saunders & Valente, 1994).

Others question their faith in God as a result of their own experiences. "The loss of my father and many young friends...It was the worst experience of my life, making me doubt God". One individual experienced death in her extended family, however, she reports very little experience in her personal life. Her "grandparents died in Ireland".

Trying to explain what death is and why it occurred to surviving family members was described by four individuals as a situation encountered as a result of death among their family and friends. "Trying" to explain death to children was reported by three of those respondents.

### Work Experiences

When examining work experience, the respondents were asked to describe the most difficult death or dying situation that they have encountered in their nursing home. Sudden / unexpected deaths, attachment to the resident / family, lingering death, bad death, painful death, residents fighting death and all deaths were described as the most difficult ( $n=3$ ). (See Appendix D)

The amount of involvement with family members of dying residents that each individual has experienced varied widely. One individual reported that she "goes out of her way to avoid the families" while others describe friendships and close emotional attachments. Over half of the respondents stated that their involvement is to provide support to the families.

Role conflict, or the difficulty experienced in responding one way as a "professional", and the urge to respond differently as a person was reported by four individuals. "Its' very hard to comfort the families and stay professional". Another caregiver felt that "You grow close to families so when they are upset, you are upset too, but you have to try to control yourself". These feelings of

conflict described by the respondents are documented in the literature for professional staff nurses (Saunders & Valente, 1994).

When respondents were asked about the type of resident it would be the most difficult to care for, their responses varied considerably. (See Appendix E). Younger residents and those who died a painful death were cited most frequently as the most difficult to handle. Several respondents (n=5) reported that all deaths were difficult. "All residents dying are difficult at an emotional and mental level due to the natural sense of loss and also on the unknown at the end of life as we know it".

When questioned about the difficult issues facing PCWs dealing with death at work, several responses were obtained (See Appendix F). A recurrent theme in the data relates to the amount of time the PCW has to spend with a dying resident. Insufficient time was reported by several respondents as the most difficult issue that an individual has had to face at work. A resident dying alone, without family members or a staff person present, was also found to be a difficult issue for a number of individuals (n=5). "The most difficult issue to deal with is time spent with the dying residents -- or lack of it. I always feel it's a very time consuming task, and wish that I had more time to be with the residents besides doing their care, it would be nice to have more time to sit and just hold their hand". The issues of code versus no code and the lack of privacy also appear in the data (n=4).

PCWs ( $n=19$ ) reported that they provided for the privacy needs of the residents and families by changing the physical surroundings, closing doors, pulling curtains, or moving residents to a private room. Providing comfort to the resident and family, and limiting interruptions were two other means of meeting the resident's privacy needs. (See Table 2)

### Responses

The respondents were asked to describe their first experience with death. The amount of detail provided varied as much as the length of time that had lapsed since the event occurred. The range of time was 1 1/2 months ago - 30 years ago with a mean of 14.74 years. One individual who experienced her first death 27 years ago describes her reaction "I ran for help; I wanted to go home".

The majority of the respondents ( $n=23$ ) reported some kind of physical response in themselves after caring for a dying resident. The types of responses include physical exhaustion, loss of appetite, headaches, nausea, inability to rest, and a strange or funny feeling. All but one of the individuals reported some kind of emotional response as well. One respondent stated "I've been in this business so long I tend to forget. I guess I felt sad but yet happy for I think there has to be something better than this world". (See Appendix G and Appendix H)



Table 2

**PCW Reported Means of Providing Privacy for Dying Residents and Their Families**

<b>Category</b>	<b><u>n</u></b>
Change physical surroundings	19
Provide comfort	7
Limit interruptions	5
Provide accessibility to staff	4
Respect wishes	2
Everything possible	2

## Coping

Respondents were asked to describe the education that they may have received that helped them in dealing with death. (See Appendix I) They were also asked to identify which of their current practices assist them in dealing with death. Equal numbers of individuals reported no training specifically related to dealing with death ( $n=8$ ) and participation in a formal education course which included a component of death education ( $n=8$ ). Others reported inservice education ( $n=7$ ) or obtaining guidance and advice from others ( $n=6$ ).

In all other questions related to coping abilities, the respondents clearly identified their coworkers as an integral part of their coping strategies. Almost half of the respondents ( $n=12$ ) reported that they talk to their coworkers to assist them in dealing with a death. The next most common responses were getting on with life ( $n=5$ ) and prayer ( $n=5$ ).

When respondents were asked what would assist them in dealing with death, talking to coworkers was identified by the largest number of individuals ( $n=6$ ). Providing good resident care was also important to the respondents as a means of coping with a death.

Only one respondent stated she did not know what would help in dealing with death while four individuals stated that nothing would help. One respondent wrote "I don't really believe there is anything to help you cope, resident or family". Another stated "Nothing, all deaths are different and individual so we deal with each as they occur".

It is noteworthy that three individuals reported having no difficulty in dealing with death or dying. One person describes her thoughts on death as “I usually don’t have trouble coping with a death at work, they are anticipatory. I feel that entering a nursing home is the first step towards your death”. (See Appendix J)

Coworkers and supervisors were listed as providing assistance to 65.6% of all respondents. Family and friends were the next most common response and two individuals reported they turned to either themselves or God to assist in their coping. (See Appendix K)

There appears to be a difference in awareness of policies and procedures in the nursing homes related to death and dying in each home. Palliative care policies were mentioned by 11 individuals while nine respondents indicated that either there were no specific policies or that they were unsure if the policies existed.

### Summary

The results in this chapter are based on the responses of 29 Personal Care Workers who are presently employed in four long term care facilities. The majority of the respondents were female with a mean age of 38.2 years. All of the respondents had some high school education and most had additional training.

The type of personal and work experiences varied widely. All individuals had cared for a dying resident within three years of the study. The majority had provided care to a dying resident within the past six months.

The responses to death that were described included physical and emotional responses. Feeling physically or emotionally exhausted was frequently cited. Loss of appetite, headaches, nausea, and inability to rest were other physical symptoms reported. Feelings of sadness, loss, peace and increased concern for others were also described by the respondents.

The most commonly used coping strategies by the personal care workers in the study were talking to coworkers, moving on with their lives and praying or reading the Bible. Coping strategies suggested by the respondents included providing good care to the residents with some individuals reporting that they had no problems in coping with dying residents.

All responses were somewhat expected when compared to the literature review. One may generalize that paraprofessional nursing staff experience similar feelings and responses as professional staff.

## CHAPTER V

### Discussion of Results

The study explored paraprofessional nursing staff responses to death which was previously an area with very limited prior research. The results of the study will be evaluated and interpreted in this chapter including a comparison of the results of this study to the literature reviewed.

The following questions were examined to guide the evaluation of the results:

1. How do personal care workers in long term care describe their personal and work experiences with the dying?
2. What coping strategies are currently used by personal care workers to assist them in dealing with death?
3. What are some potentially helpful coping strategies identified by personal care workers in Homes for Special Care related to dealing with death?

#### Demographics

The demographic attributes of the respondents were examined to determine if any relationships could be identified. The researcher examined each of the categories individually in an attempt to identify patterns in the responses. For example, the age of the individuals was examined to determine if a relationship existed with their coping ability. Length of experience and responses to death were also examined by the researcher. Several potential

relationships were reviewed with the same result. There were no identifiable trends by demographic attribute within this sample. Perhaps the response rate was too low to have enabled the researcher to easily identify trends.

### Personal Experiences

As expected, the number of personal experiences reported by the respondents varied from no experience in their personal lives to traumatic events and multiple experiences. The most prevalent response was that individuals had experienced deaths in both their immediate and extended families. Experience in dealing with death is described in the literature as being inversely related to death anxiety in individuals (Denton & Wisenbaker, 1977; Murphy, 1986). Thus, the respondents in this study may be expected to have lower levels of death anxiety. For the purposes of this study, death anxiety in the personal care workers studied was not specifically examined.

The range of emotional responses described by the respondents is very similar to the information reviewed on grief and bereavement. Feelings of loss, sadness and emotional exhaustion were most commonly reported in this study. In addition to the reported responses in this study, thoughts of one's own death, crying, anger and anxiety were documented in the literature (LeShan, 1969, Menzies, 1960, Saunders & Valente, 1994).

In terms of emotional responses the respondents in the study reported feelings of loss, helplessness, sadness, devastation, and fear of the unknown.

All of these responses would be expected given the relationships developed in one's personal life. As family members with diverse roles, one would expect that the practical details of dealing with death would be commonly reported. Making funeral arrangements and estate management were reported by the respondents.

As well, the health care field is a female dominated industry. Typically individuals who work in the field are thought to possess an aptitude to caring. Providing support to others would not be an unusual role for those individuals. Several respondents reported that their personal experiences with death focused primarily on supporting the surviving family members. Explaining the loss of a loved one to children in the family has been reported as a situation personal care workers have encountered in their personal lives.

### Work Experiences

The personal care workers in this study identified several patient symptoms and behavior that were described as the most difficult situations they have encountered in their nursing home or that they would anticipate to be difficult situations. Caring for residents suffering pain, who are younger in age, or dealing with residents who are afraid to die were common responses in this study. These responses are very similar to those reported by Alexander (1990) in a study of 38 palliative care nurses. Both the personal care workers in this

study and the palliative care nurses in Alexander's (1990) study have described those situations as stressful when caring for dying residents.

Strank (1972) questioned nurses in a variety of settings to determine causes of stress in caring for the terminally ill. The nurses in that study identified stress borne with identification with the patient, caring for younger patients, if the patients appearance was altered due to treatments, and if the patient or family had not been informed of the prognosis. Coping with unexpected or sudden death was also identified as increasing nurses' stress levels (Saunders & Valente, 1988). Similarly, personal care workers in this study reported that attachment with the resident or family and unexpected death was a particularly difficult experience. However, only one respondent in this study reported that changes in a resident's physical appearance was the most difficult situation that had been encountered. This may be explained in part by the settings in which the deaths occurred. In Strank's study, nurses were caring for a different type of patient. That is, those patients may have received chemotherapy or had their appearance altered due to surgery. Typically, the nursing home resident would not have endured those types of treatments so that the number of dying residents with altered appearances would be less.

As early as 1966, researchers were identifying that nurses are particularly vulnerable to the deaths of patients whom they like, have known for long periods of time, whose death carries high social loss, and those patients with whom there is involvement with the family (Quint, 1966). The personal care workers in



this study reported all but two of the aforementioned "stressful" death experiences. The patient whose death carries high social loss and caring for residents who were not informed of their diagnosis were not identified in this study. Dealing with residents dying from lingering deaths, residents dying alone, and self imposed deaths were described in the study as difficult situations.

It was identified by the respondents that it is more difficult to care for residents with whom they had formed "attachments". Robbins (1992) in his study involving nursing home staff noted that the staff frequently form strong interpersonal bonds as a result of the long term exposure to their care. One respondent summarized the situation as follows: "Being with the residents so much you become very attached so their death becomes very personal". Once again the literature provides support to the responses of the personal care workers in this study.

Thus, the responses obtained in this study have support in the literature reviewed. Although the literature focused primarily on professional nursing staff, one can easily identify the common experiences. The personal care workers in this study experienced very similar situations to the professional staff previously studied.

One other area that was explored within this study was how PCWs provide for privacy needs of the residents. In the nursing homes involved in the study, there are very few private rooms. Thus, the researcher initially thought privacy may be a concern for some caregivers. The respondents reported that

they were able to change the physical surroundings by closing doors and pulling curtains between the beds in an attempt to increase the privacy for residents and their families. The issue of lack of privacy appeared in the responses from 13.8% of all respondents. This issue was not prevalent in the literature reviewed. Perhaps this is due in part to the physical setup of hospitals and hospices where private rooms are more readily available.

### Emotional and Physical Responses

Respondents were able to recall their first work experience of caring for a dying resident. The amount of detail provided varied for each respondent, however, when one considers the average length of time since that experience was 13.48 years; it is interesting that all respondents had memories of the experience.

The literature suggests that responses reported by the personal care workers have also been reported by professional nursing staff when caring for dying residents. Feelings of sadness, crying, anger and anxiety have been identified as emotions linked with grief (Alexander, 1990, Feldstein & Gemma, 1995, Saunders & Valente, 1994, Sumaya-Smith, 1995). Disruptions in sleep patterns, loss of appetite, interest, concentration and social functioning are responses described in detail in the literature (Saunders & Valente, 1994).

In the literature, stress has been reported to be manifested in a number of ways. Illness, tiredness and voicing grievances are often symptoms of stress.

(Alexander, 1990, Feldstein & Gemma, 1995, Saunders & Valente, 1994, Sumaya-Smith, 1995). Stress described by those caring for dying patients (Mandel, 1981). Anger, anxiety, feelings of powerlessness, depression, sadness, and role confusion were also identified by professional nurses as causing stress when caring for dying residents (Mandel, 1981)

The personal care workers in this study exhibited similar symptoms. Physical exhaustion, loss of appetite, headaches, nausea, crying, and inability to rest are all reported by the respondents. Feelings of remorse, relief, nervousness, sadness, emotional exhaustion and a sense of loss are also reported. These responses would indicate that PCWs respond to death in a similar manner as the professional staff who were studied by previous researchers.

### Coping

Nurses frequently maintain social distance from their patients and minimize the amount of time spent with them in an attempt to minimize the stress levels (Glaser & Strauss, 1965; Kubler-Ross, 1969; Quint, 1966, Stoller, 1980). The personal care workers in this study did not report similar coping strategies. In fact, a number of concerns were reported about the lack of time available to spend with the dying resident.

The strategies commonly used by this group were to talk to coworkers, supervisors, and family or friends. Others simply stated they have to get on with

their lives. Some individuals reported that prayer or reading the Bible assisted them in coping with the death of a resident.

Providing good resident care was also important to the respondents as a means of coping with a death. A similar comment was made by professional nurses who felt some satisfaction if they were able to help the resident die a "good death" (Saunders & Valente, 1994).

The amount of education or formal training received that assists the personal care worker in dealing with death varied as well. Formal courses were described by 23% of all respondents while 21% reported that palliative care education sessions have assisted them in dealing with death. It would appear that education programs, when available, do assist the personal care worker in caring for dying residents.

#### Assistance with Coping

Researchers have suggested that open ward meetings and peer counseling could be useful in helping nurses cope with dying (Mandel, 1981; Nutall, 1977; Sheard, 1984). Allowing a bed to remain empty for twenty-four hours was also listed as a helpful strategy. Some researchers suggest that "institutions try to make death invisible" (Sumaya-Smith, 1995) while others suggest that staff are expected to cope using stoicism and denial of feelings (Hare & Pratt, 1989; Mandel, 1981)

This appears to be the case in the nursing homes in this study. One respondent stated “We are not able to grieve. We just fill the bed and move on, the beds aren’t even cold most of the time and we’re expected to carry on like nothing has happened”. As mentioned previously, the literature suggests that leaving a bed empty for 24 hours would be recommended, however, the PCWs did not make similar comments.

Talking to coworkers, providing good care, prayer and education were suggested strategies by the respondents. The literature supports open ward meetings and the researcher suggests that this process be formalized. Knowledge of policies and procedures varied greatly with the respondents and one may suggest that the involved facilities consider some education for the staff.

### Discussion of Methodology

The design of this study offered the respondents two options for participation. The first option was to complete a questionnaire. The respondents could attend a group session at their workplace and complete the questionnaire during the work day. The PCWs at the participating facilities had been included in many focus groups conducted by the employer in the past. It was initially expected that a group setting would optimize the response rate. This did not occur for this study. The total number of individuals who

participated in this way ranged from one to ten with the total being 19. Ten of the questionnaires were returned directly to the researcher.

Contact persons at each facility reported to the researcher following completion of the study, that there had been numerous focus groups occurring within the facility around the time of data collection. The data collection phase also occurred at a time when staff summer vacations had commenced. There was a reported "shortage of replacement staff" at two of the facilities which may have impacted on the number of available participants during a work day.

The proposed participants may have chosen to participate by completing the questionnaire on their own and returning the completed form directly to the researcher. In retrospect, a collection box in a visible location within each facility may have reminded and encouraged individuals to respond.

All of the proposed participants were invited to be interviewed by the researcher if they wished. This opportunity was described in the introductory letter sent to all proposed participants. There were no requests for interviews for this study.

Perhaps, a higher response rate would have been achieved if the researcher had used interviews with selected individuals. A letter sent to a random sample of the study population requesting their assistance may have resulted in a higher response rate.

## CHAPTER VI

### Summary and Recommendations

The limitations of the study, implications for nursing practice, research and conclusions are presented.

#### Limitations of the Study

The response rate of 29 individuals is quite low considering that the number of potential respondents was 110. The timing of the data collection may have had an impact on the total number of respondents. Typically staff vacation schedules begin in the first part of June which was when the data were collected.

After completing the data collection, there was some discussion held with a representative from each facility. The representatives indicated that June was an “extremely” busy month in the Homes with several projects happening in a short time frame. This too, may have had an impact on the number of respondents.

The study was conducted within one company. Management within the company have stated that policies and procedures are currently available to staff and palliative care programs are being developed. Perhaps there is a greater awareness of death and dying within these facilities as a result of recent quality initiatives.

All respondents had completed some high school in this study with many (55%) having completed either a PCW or a CNA program. This sample may not

be truly representative of the industry. The Homes in the study have recently upgraded their requirements for their staff. High School graduation is now the minimum accepted education level for PCW staff within the company. An informal telephone survey in the geographical area of the Homes indicates that some facilities require Grade 10 education levels and some require Grade 9. Others do not stipulate the grade level but would require a PCW course. Thus one may question whether this sample is truly indicative of the general population of Personal Care Workers.

#### Implications for Nursing Practice

Overall, the physical and emotional responses to death and dying reported by the respondents in this study were similar to those reported by professional nursing staff in other studies. Therefore, opportunities for education and training for paraprofessional staff in dealing with death should be made available.

Talking with coworkers was identified as a present coping strategy as well as a desired strategy. Professional staff and the management of the Homes need to recognize the support system for the staff and perhaps formalize the processes. Unit meetings, or bereavement follow-up meetings should be included in the unit routines following a death. Informal support systems should also be recognized and encouraged.



Prayer and reading the Bible were also described by the respondents as a useful strategy to assist in dealing with death. Memorial services could be held within the Homes and should involve interested paraprofessional nursing staff.

Three respondents (10.3%) reported that there is no time to grieve. One individual reported that “the bed is very seldom cold before someone else is in it”. The financial impact on the facilities and the external pressures to maintain full occupancy are apparent. If management would like to meet both staff needs and financial pressures, options need to be explored. Perhaps the beds could be filled quickly if alternate formal means of expressing grief were made more accessible to the staff.

As described in the literature, facilities sometimes try to make death invisible. It appears by the responses in this study that some individuals feel grieving is not “encouraged” within the facilities. Therefore, given limited time and resources available within each facility, the researcher would suggest that formalized practices be reexamined in an attempt to provide more support to the paraprofessional staff. The needs of the professional staff within the facility also need to be considered when programs or processes are being developed.

Some of the participants indicated feelings of guilt at not being able to spend as much time with the dying resident or their family as they would have liked. The use of volunteers to stay with dying residents or encouraging family members to be present may assist those PCWs who feel that they do not have

the time necessary to “properly care for the dying resident”. The administration of each facility should consider a formalized program which would address the issue of lack of time thereby assisting the staff and the residents and families.

The level of knowledge regarding policies and procedures within the Homes varied as well. An ongoing inservice education program could be useful in increasing staff awareness of policies and procedures related to death and dying.

### Implications for Nursing Education

The findings of this study could be used to assist educators in planning educational programs. The respondents clearly identified coping strategies currently being used, potentially helpful coping strategies, types of individuals it would be most difficult to care for, and the type of responses experienced by PCWs caring for dying residents. This information could be used to guide educational program planning. Each program should also be tailored to the participating group. Due to the limited response rate of this study and the limitations related to generalization, a pretest or needs assessment would be recommended prior to the introduction of an educational program within a particular facility. Staff input would be essential to the success of the program.

### Implications for Nursing Research

Further research is suggested in this area. This study was completed primarily in an urban setting where the cultural milieu may vary from a rural setting. Future studies should consider the types of communities where the Homes exist.

There appears to be a need for educational programs for paraprofessional staff. Research involving professional staff has indicated some benefits with education. A comprehensive review of the effects of death education for all levels of staff should be completed prior to the development of an education program. Death anxiety should be measured pre and post education.

The inclusion of theories of social support could prove beneficial to future researchers. The implications of using a model as a guide in research would need to be considered.

Attitudes toward the elderly were not examined in this study. It has been suggested by the literature that attitudes toward the elderly have an impact on the type of care provided in nursing homes. There have also been references to the relationship between attitudes toward the elderly and death anxiety in this population. Further study is needed in this area.

Quantitative research dealing with levels of anxiety, stress, and the impact of educational programs or the formalization of coping strategies may prove useful to assist nursing administrators in developing programs to assist

their staff. Research involving professional staff should be considered seriously as potentially similar results could occur with this group.

A comparative study involving professional and paraprofessional staff within the same facilities could assist in the identification of coping strategies. Development of programs would be dependent on future research.

Paraprofessional staff in this study have experienced similar responses to dealing with death as have professional staff in other clinical areas. The current coping strategies used by PCWs also reflect available research involving professional staff. The amount of training and experiences vary greatly and should be considered when program development is considered. Overall, there is a need for more research and support to assist paraprofessional nursing staff working in long term care centers to effectively manage caring for the dying residents.

## APPENDIX A

### Letter to Research Review Committee

Site 2 Box 23 RR#7  
Armdale, Nova Scotia, B3L 4R7  
(902) 852-5499  
March 29, 1996

Chairperson  
Research Review Committee

Dear Sir or Madam:

I am a graduate nursing student at Dalhousie University in Halifax, Nova Scotia. In partial fulfillment of my degree I am proposing to undertake an exploratory and descriptive study to explore the responses of paraprofessional nursing staff to death in a long term care facility. Your approval to conduct this study is needed if work is to proceed beyond the proposal stage.

As you are probably aware, paraprofessional nursing staff are the primary caregivers in a long term care setting. They are often involved in caring for dying residents. Many studies have been undertaken in the past related to nurses attitudes toward death, stress as a result of dealing with death and dying, and grief reactions. However, very little research has focused on the responses of paraprofessional caregivers in long term care.

This study is intended to involve up to 50 paraprofessional nursing staff at your facility. They will be contacted initially by a letter requesting their cooperation. If they are willing to participate, they may complete the forwarded questionnaire and return it to the researcher or they may attend a group meeting to complete the tool at the workplace.

Demographic data will be analyzed using descriptive statistics while the remaining open-ended questions will be subject to a content analysis approach.

A pilot study will be carried out in a separate facility to determine the reliability and validity of the research instrument. Consistency in analysis will be verified by an independent person familiar with the technique.

I am very interested in learning more about how paraprofessional staff respond to death. If permission is obtained to conduct this study, I hope to use the findings to enlighten health care workers and to provide a basis for further study.

I have included a copy of the proposal and the data collection instrument for your perusal. I would be pleased to answer any questions you may have regarding this study.

Thank you for your consideration.

Sincerely yours,

Nicole Tupper

Graduate Student

Master of Nursing Programme - Dalhousie University

Dr. Margaret Arklie Thesis Supervisor, Dalhousie University School of Nursing

494-2390

## APPENDIX B

### Letter to Proposed Participants

126 Purcells Cove Rd  
Halifax, NS, B3P 1B5  
(902) 477-8051

June 14, 1996

Dear

I am a nurse researcher who has been working in a long term care facility and I am interested in learning about how Personal Care Workers deal with the death of residents. I am currently conducting a research study as part of the Masters of Nursing programme. As you are presently employed in a long term care facility, I am requesting your participation in my proposed study. My research has received Ethical approval from the Dalhousie Faculty of Graduate Studies Ethics Committee and the Research Review Committee of your facility.

If you agree to participate in this study, you may choose to either complete the enclosed questionnaire and return it to the address listed above or you may attend a group session to be held at your workplace to complete the questionnaire. A session will be held at Armview Estates on Wednesday June 19, 1996 at 2:30 p.m. The questionnaire will take 30-60 minutes to complete.

If you wish to participate in the study but would prefer to meet with the researcher or if you wish to be interviewed after you have completed the questionnaire, please send me your name and address on a separate sheet of paper. I will contact you after I have received this information indicating your interest.

Your participation is voluntary and there will not be any negative consequences if you choose not to take part. Your employer will not be informed of who is participating in the study and who is not. If you do assist me in this endeavor, your name and answers will be kept anonymous and confidential.

Thank you in advance for your cooperation.

Sincerely,

Nicole Tupper  
Graduate Student  
Master of Nursing Programme - Dalhousie University

Thesis Supervisor - Dr. Margaret Arklie  
Dalhousie University School of Nursing - Graduate Programme  
Phone 494-2390

**APPENDIX C**

**PARAPROFESSIONAL NURSING STAFF RESPONSES TO DEATH IN A LONG TERM CARE SETTING**

**PART A**

1. AGE \_\_\_\_\_ 2. SEX \_\_\_\_\_

3. RELIGIOUS AFFILIATION \_\_\_\_\_

4. What is the highest level of education you have achieved?

- \_\_\_\_\_ Less than Grade 9
- \_\_\_\_\_ High School (Grade 9-12)
- \_\_\_\_\_ Some Community College
- \_\_\_\_\_ PCW Course
- \_\_\_\_\_ CNA Course
- \_\_\_\_\_ Some University

5. How long have you been employed in a nursing home?

- \_\_\_\_\_ Less than 1 year
- \_\_\_\_\_ 1 - 5 years
- \_\_\_\_\_ 6 - 10 years
- \_\_\_\_\_ Greater than 10 years

6. How many years experience do you have in caring for dying residents?

- \_\_\_\_\_ Less than 10
- \_\_\_\_\_ 11-20
- \_\_\_\_\_ 21 or more

**PART B**

**Personal Experiences**

7. Please describe any experiences you have had with death involving people who have been close to you

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**8. What situations have you encountered as a result of a death among your family or friends?**

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**WORK RELATED EXPERIENCES**

**9. When were you last present when a resident was dying or died?**

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**10. Please describe the most difficult death or dying situation that you can remember happening in your nursing home.**

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**11. What involvement have you had with families of dying residents and how did it affect you?**

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**12. What type of resident do you think it would be the most difficult for you to care for when he or she is dying? Why?**

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**13. What are the most difficult issues that you have had to face at work about death and dying? Why?**

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**14. How do you provide for the privacy needs of the dying resident and their family?**

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**RESPONSES**

**15. Please describe how you responded the first time that a resident you cared for died. When did this occur?**

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**16. What physical responses have you noticed in yourself after you cared for a dying resident?**

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**17. What emotional responses have you noticed in yourself after you have cared for a dying resident?**

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**COPING**

**18. Please describe any inservices, education courses or meetings that have helped you in dealing with death?**

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**19. What things do you do to help you deal with the death of a resident?**

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**20. What things do you think would help you cope with the death of a resident?**

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**21. Who do you turn to for assistance when you have a problem dealing with a dying resident?**

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**22. Please describe any policies and procedures at your nursing home which deal with caring for a dying resident.**

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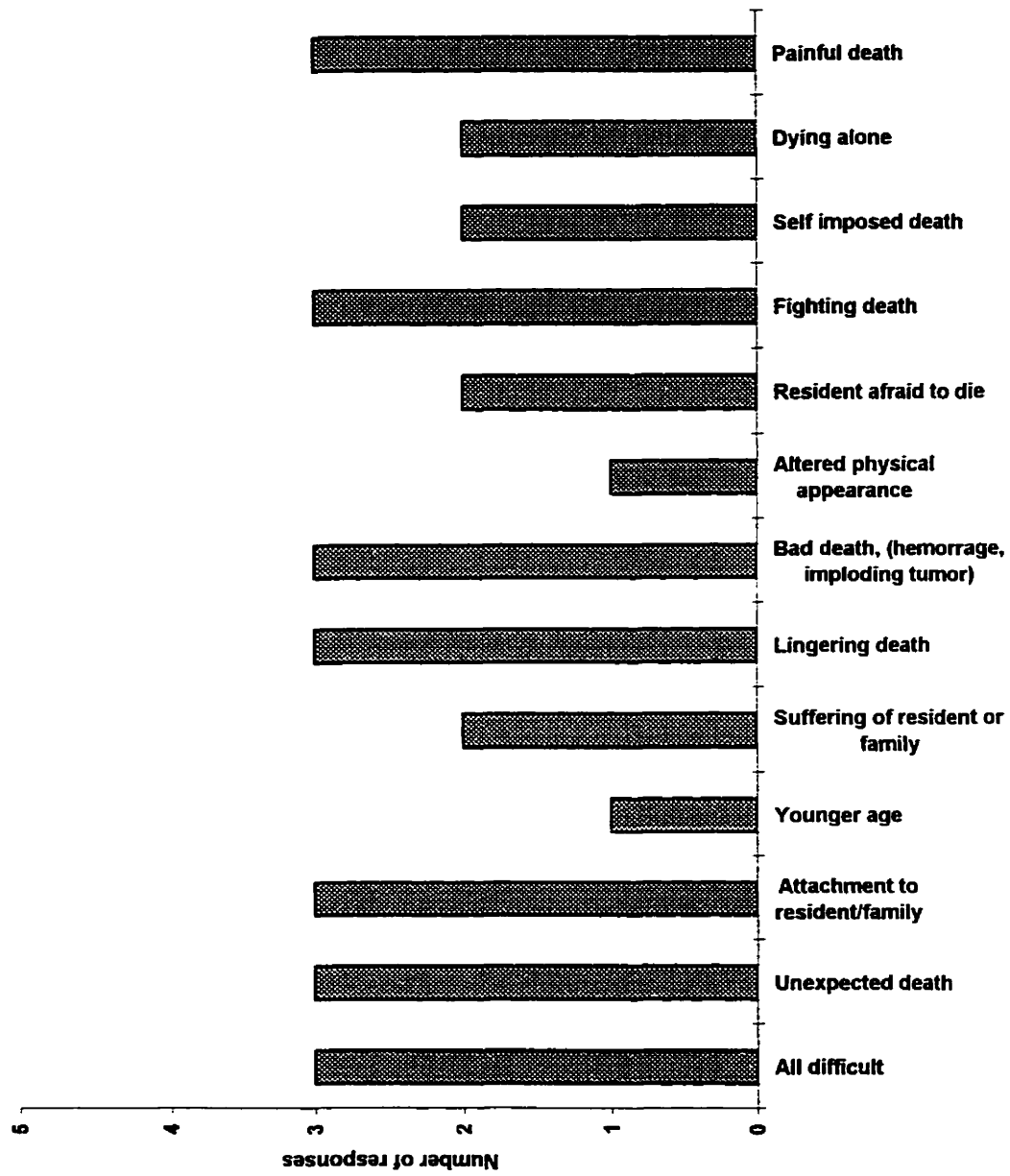
**23. Please make any comments related to your experience with death that you would like to share but have not been covered in the questions.**

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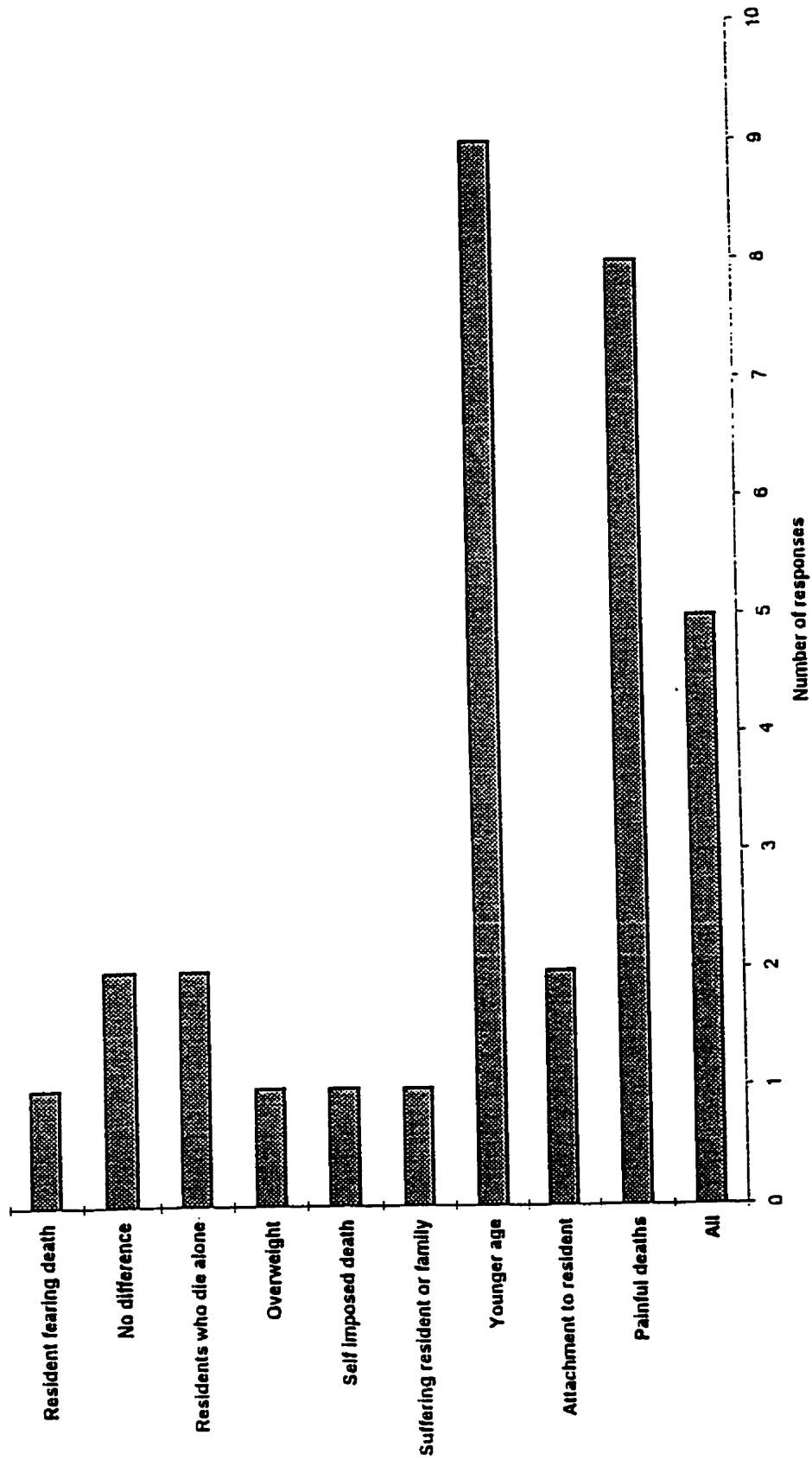
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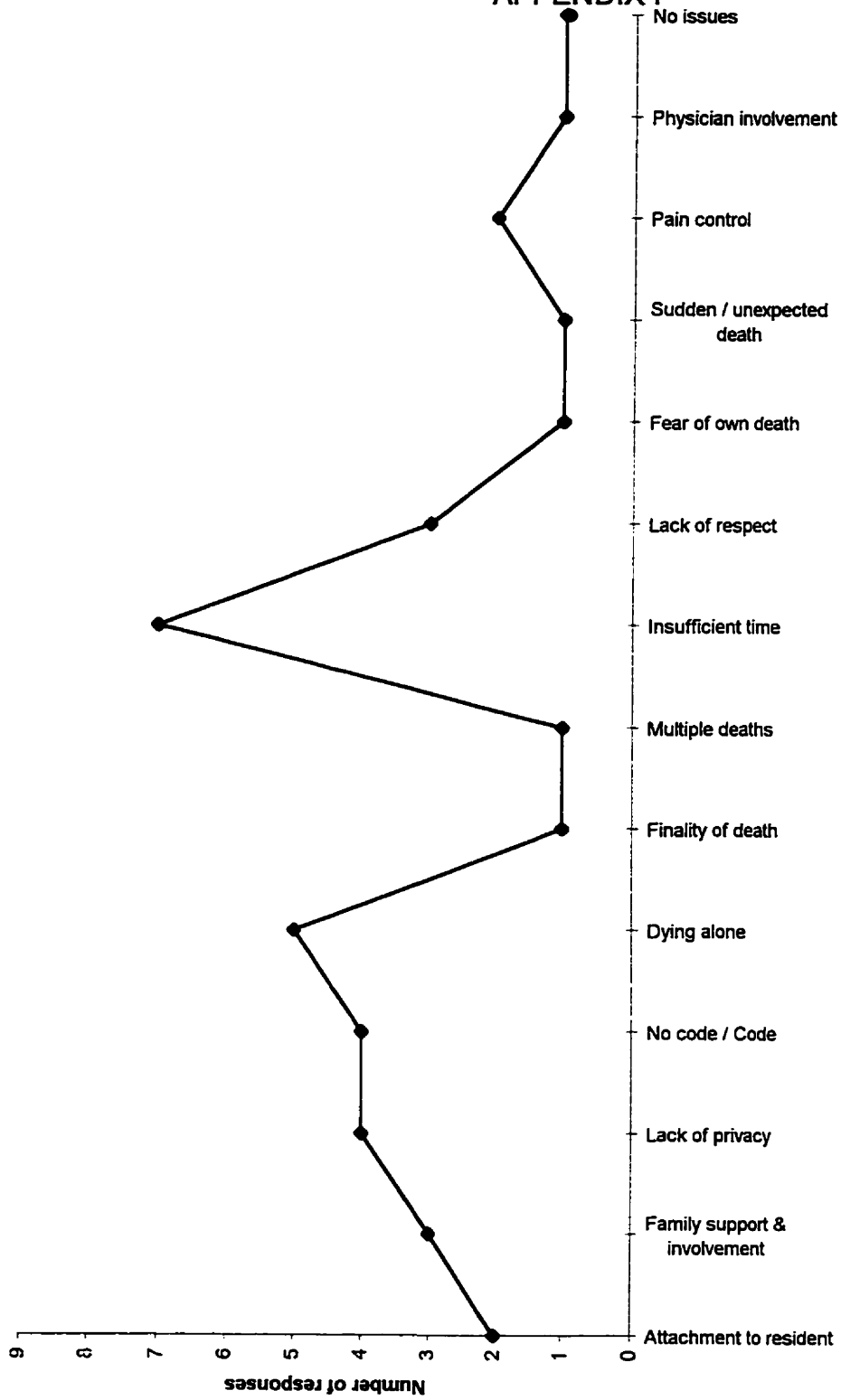


**Most Difficult Death or Dying Situation Reported by PCW Staff**

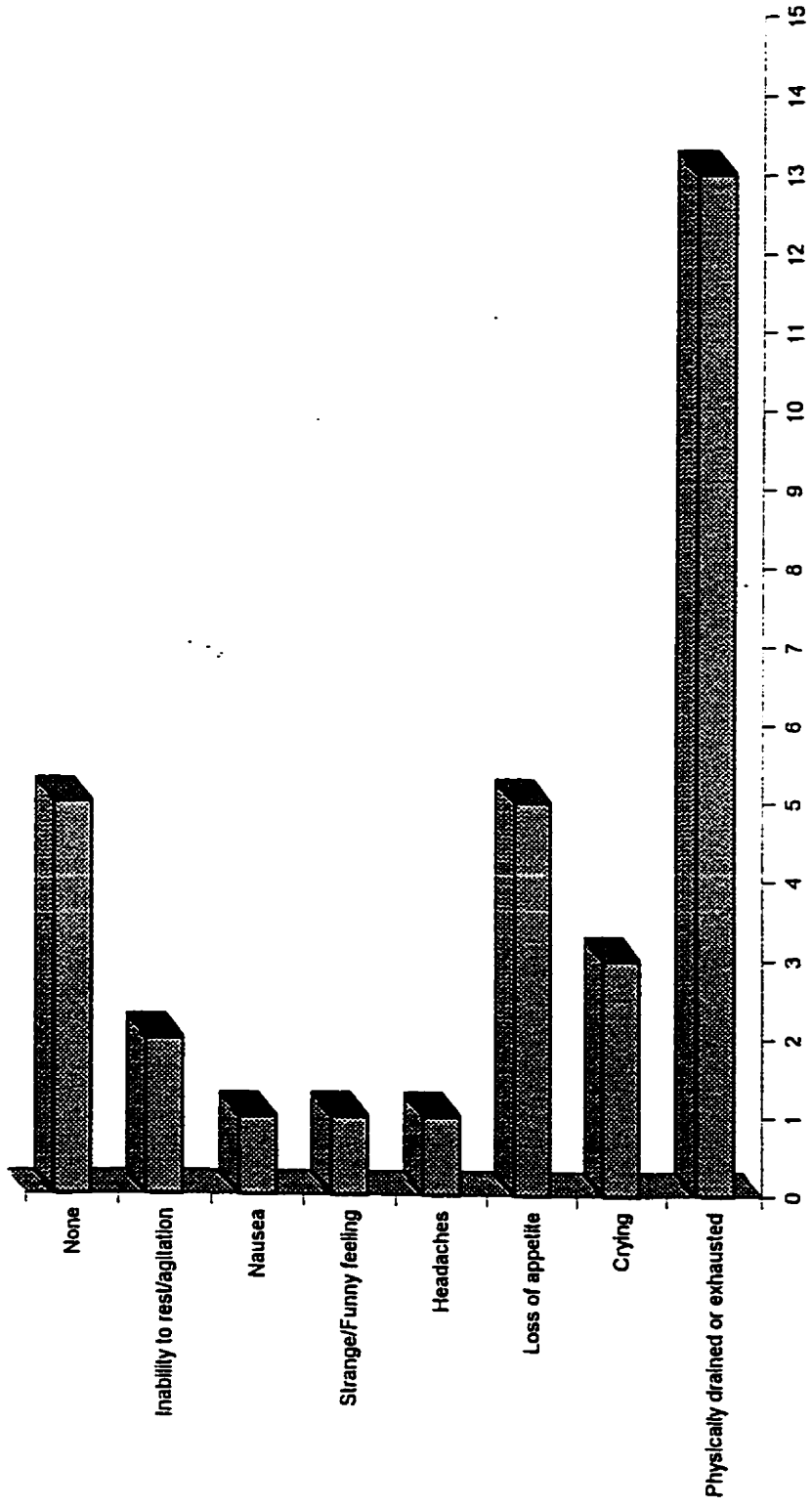


**Types of Dying Residents Difficult to Care for as Described by PCW Staff**

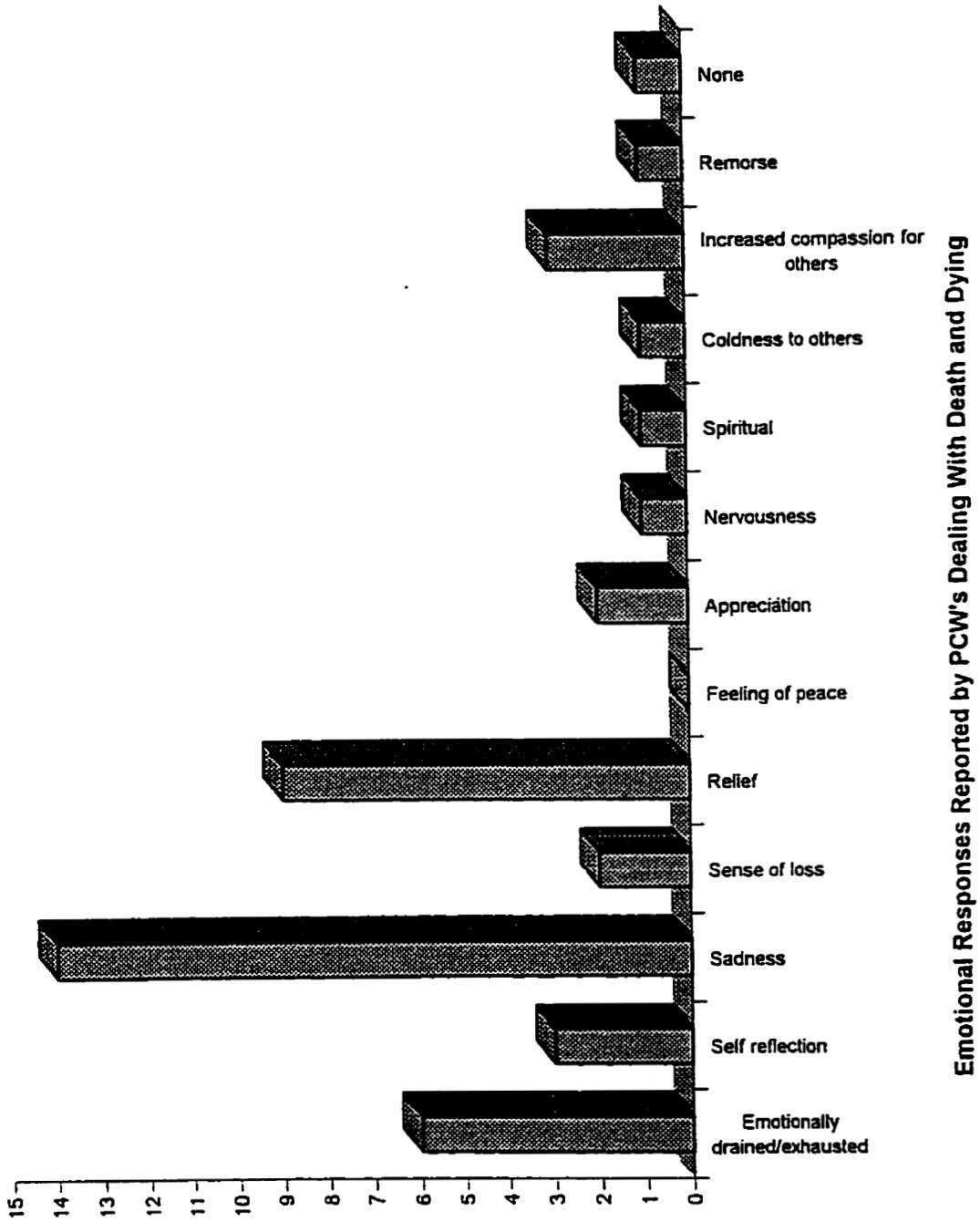
# APPENDIX F

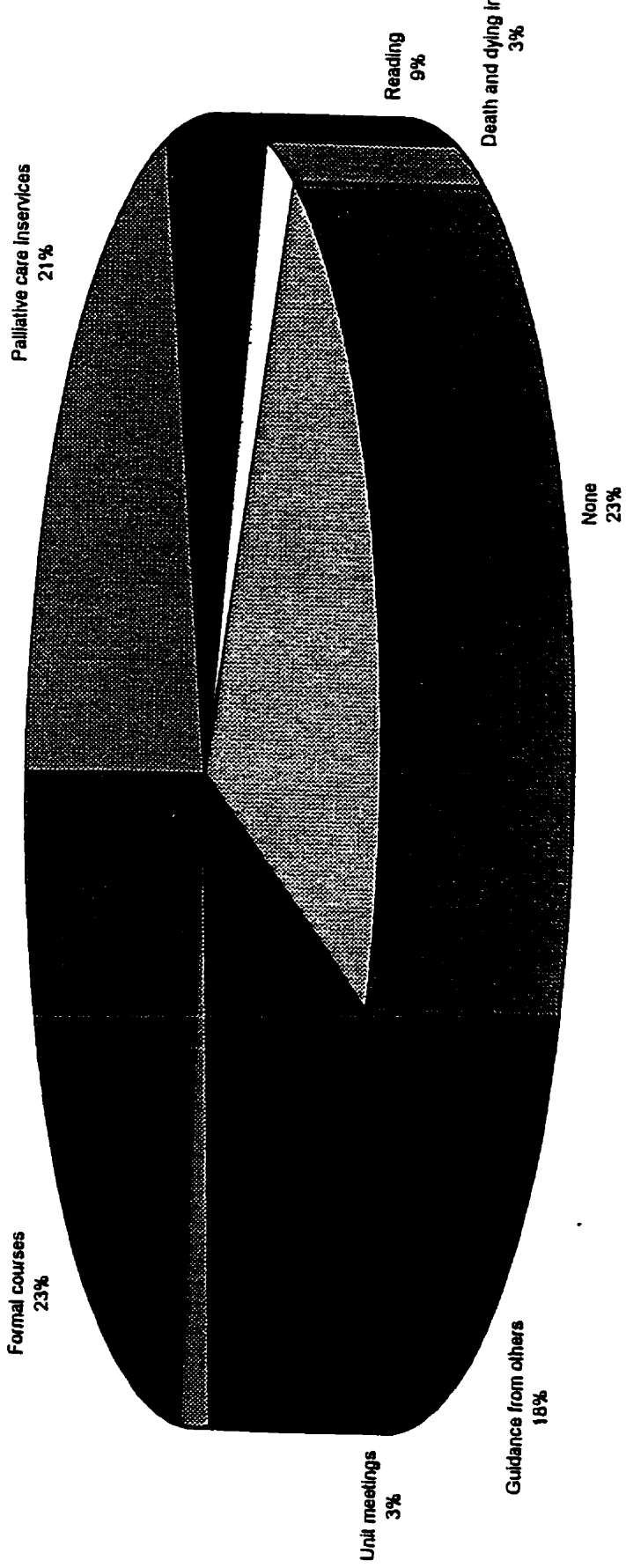


Difficult Issues Faced by PCWs Dealing With Death at Work



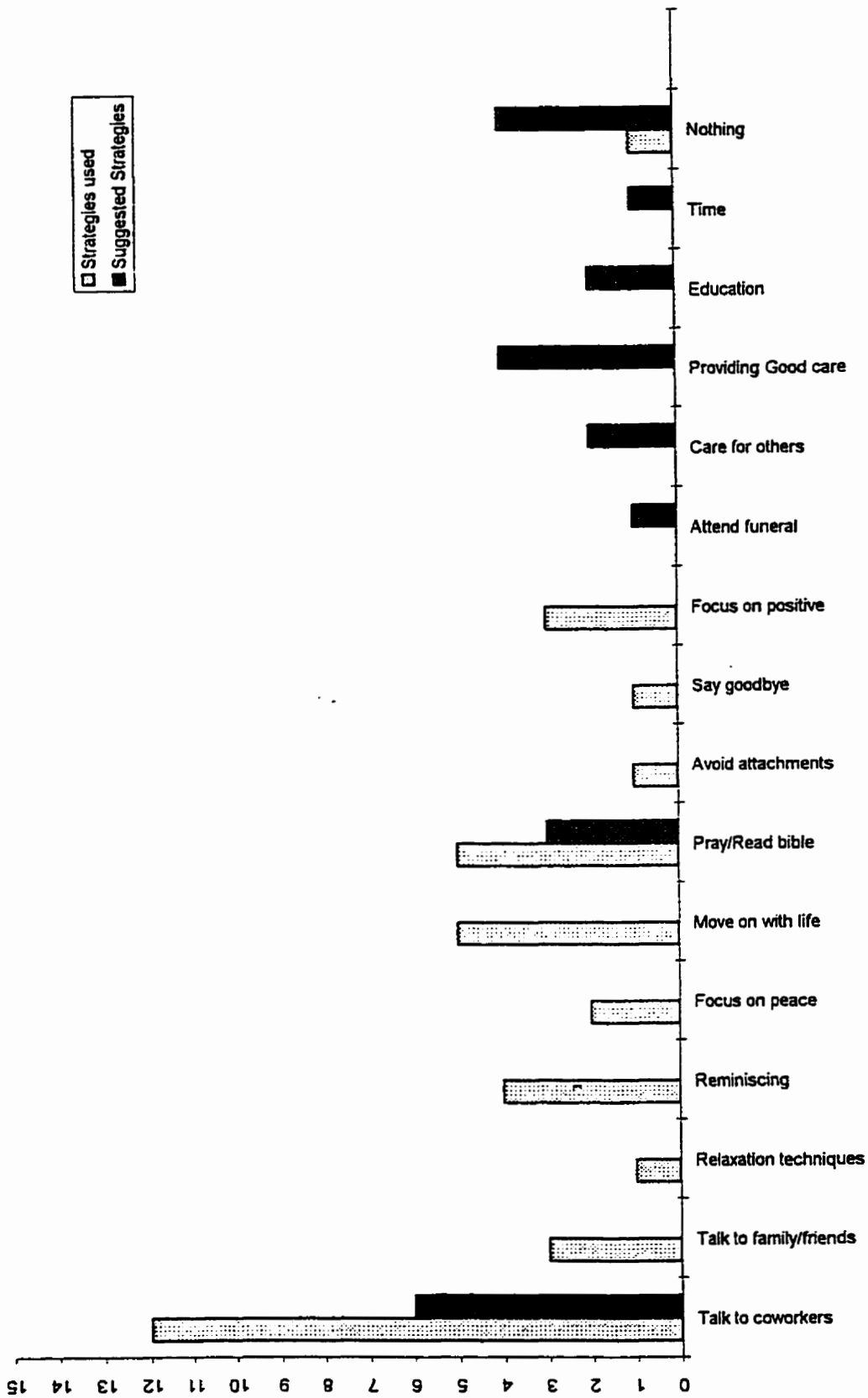
Physical Responses Reported by PCW's Dealing With Death and Dying



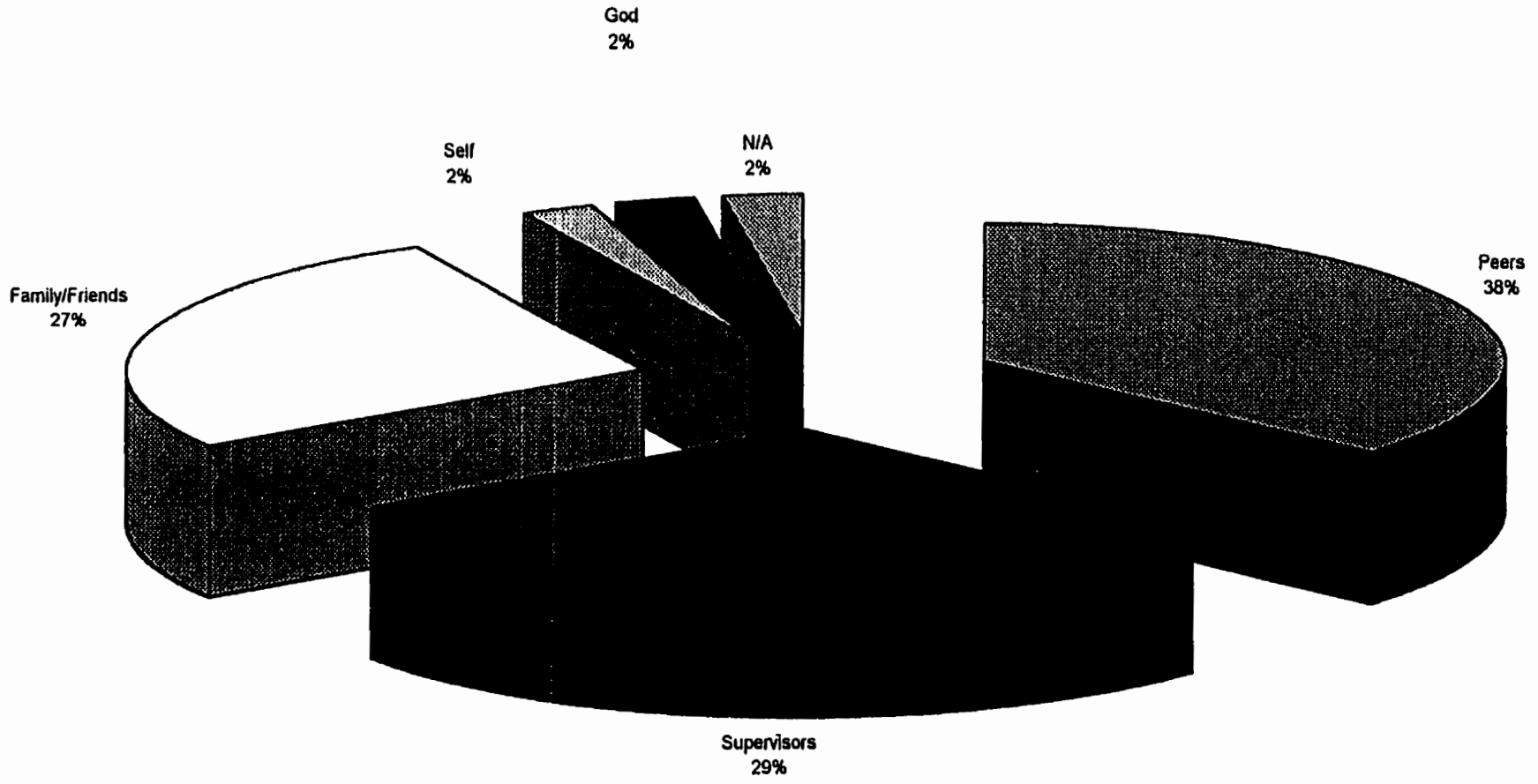


**Education Received by PCWs Related to Death and Dying**





Coping Currently Used by PCW's and Strategies Suggested as Useful by PCW's



**Sources of Support for PCW's Dealing With Death and Dying**

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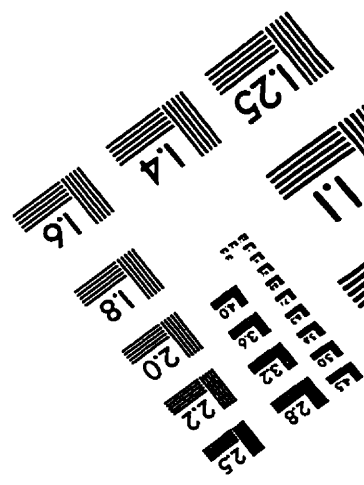
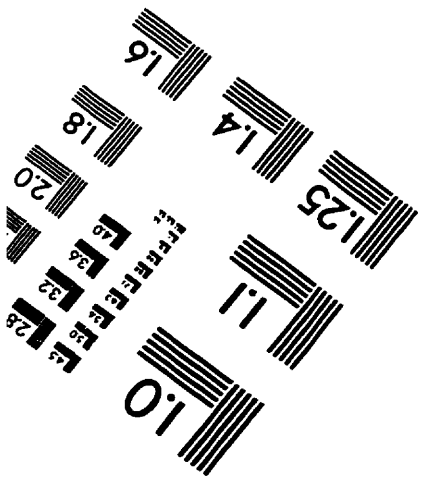
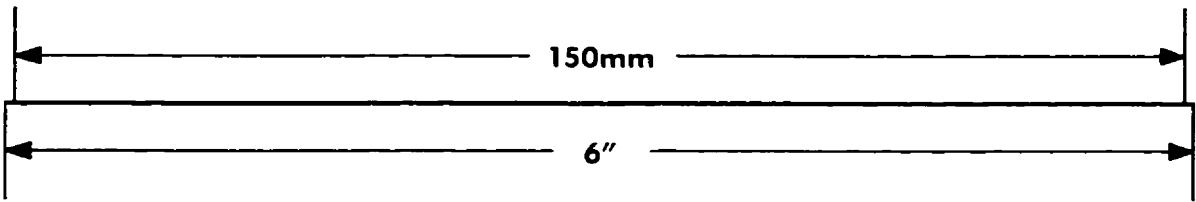
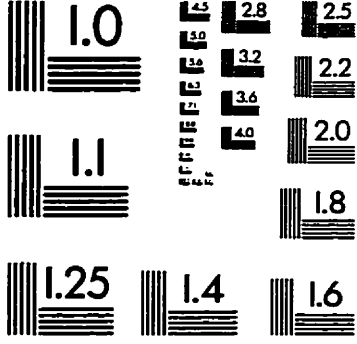
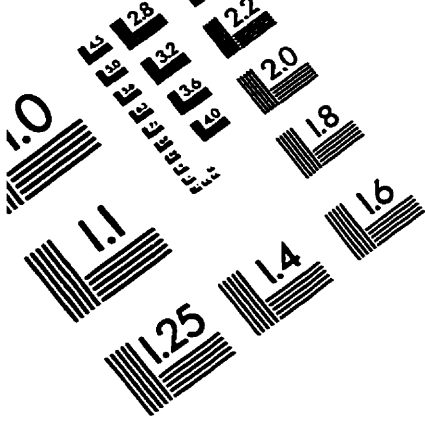
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**APPLIED IMAGE, Inc**  
1653 East Main Street  
Rochester, NY 14609 USA  
Phone: 716/482-0300  
Fax: 716/288-5989

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