2001

Healthcare providers' experience of chronic grief in a pediatric subacute facility

William Andrew Sacks

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HEALTHCARE PROVIDERS' EXPERIENCE OF CHRONIC GRIEF IN A
PEDIATRIC SUBACUTE FACILITY

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
William Andrew Sacks
June 2001
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PEDiatric SUBACUTE FACILITY

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ABSTRACT

The purpose of this study was: (1) to evaluate the level of grief experienced by healthcare providers in a pediatric subacute facility, (2) to compare the levels of grief between different groups of healthcare providers (Certified Nurses' Aides, Licensed Nurses, and Respiratory Care Practitioners), and (3) to describe the personality/demographic factors that influence a healthcare provider's ability to cope effectively with compound grief. The research followed a descriptive, correlational design, using a combination of 2 surveys, one for demographic variables, another to measure the level of grief experienced. The specific issue addressed was factors that affect healthcare providers' ability to cope with compound grief in a pediatric sub-acute facility. Analysis was conducted using a variety of univariate, bivariate (t-test, chi squared), and multivariate techniques (step-wise multiple regression) to describe the sample population and significant correlations among the sub-samples (disciplines), as well as among the various independent and dependent variables. Four variables were identified for the multiple regression: level of religious involvement,
other losses, years in current position, and level of support system. The combined effect of these 4 variables accounted for 25.1% of grief experience in this model. To understand more fully the factors that influence a healthcare provider's ability to cope effectively with compound grief will aid in the development of effective interventions to assist them in developing the skills to withstand and resolve the grief.
DEDICATION

This project is dedicated to the staff at Totally Kids Specialty Healthcare, not only for their on-going support and participation in this study, but more importantly, for the loving care they provide the children. Their's is true dedication.
ACKNOWLEDGMENTS

I would like to thank the administration and staff at Totally Kids Specialty Healthcare for their support and participation in this study; without their efforts this study would not have been possible. And to Elise Lev, Ed., R.N., C.S., for her generous consent to use her unpublished material. Also, to my classmates, who kept me going when my energy waned; we got each other through this. My heartfelt thanks to Dr. Rosemary McCaslin, mentor and academic advisor, who’s tireless efforts on my behalf reminded me that “good enough” is never good enough. To my dear friends, who for three years put up with my erratic moods and behavior. And to my family, I do not have the words to express my love and appreciation for their endless patience and support of this project, and throughout my life. Especially to my mother - friend and role model - whose MSW commencement I attended in June, 1961. Now, forty years later...
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NO TIME TO CRY

It happened again today;
My patient died and...
There was no time to cry.

He arrested in X-ray
QUICK! Call a code. QUICK! Do CPR.
I’m too busy with compressions, defibrillation
...There was no time to cry.

Hurry! X-ray needs the room.
QUICK! They have patients backed up.
PLEASE! Just a few minutes alone, but
...There is no time to cry.

We take him back to the department.
His room is filled with another,
No private place to prepare his body...
QUICK! The man in the next bed has some runs of V-tack.
HURRY! The woman is crying in pain and vomiting.
PLEASE! Just a few minutes alone, but
...There is no time to cry.

HURRY! Ambulances coming Code Three.
QUICK! Take the body to the morgue.
HURRY! Run back to the department.
How many times can I push down the tears and sorrow inside?
...There is no time to cry.

(Ams, 1993)
At some time in our lives we will all face death - the death of parents, other family members, friends, and ultimately our own death. We may have our first direct encounter with death at a very early age, maybe later, maybe several deaths in rapid succession in one's close circle.

Many healthcare providers face death on a regular basis, especially those who work in such settings as oncology units, intensive care units, hospice settings, etc. Death becomes an all too familiar part of the lives for many of these workers. It was believed in decades past that the nurses' primary responsibility in these instances was to assist the families with comfort and grief support, that they did not grieve themselves for these patients since they were to remain objective and emotionally detached from their patients. This old school of thought was more a myth than reality. It is now widely recognized that nurses and other healthcare providers do care about their patients, they do develop relationships with their patients, and they do grieve for these losses. As a person, the healthcare provider may feel sad and tearful,
but as a professional, may be reluctant to display strong emotion in front of the bereaved family, peers, or other patients. Often, patient deaths in these settings happen in close succession, allowing insufficient time to resolve the grief from one death before the next occurs, and then the next, and so on. This is termed compound grief in the current literature, and can lead to excessive stress on the job, job burnout, etc. So, how do healthcare providers cope with this situation?

As a medical social worker in home health and hospice settings, this researcher has long been amazed with how patients cope with their impending death and still go on with their lives. All people do this to some degree; that is, have awareness of their own mortality (often reminded of this by the deaths around them) and yet manage to go on with life in a meaningful way. The subjects of this study work in a particularly difficult medical setting and are faced with numerous deaths per year. They provide care in a 50-bed pediatric sub-acute medical facility; the children, their patients, are for the most part neurologically devastated, severely to profoundly mentally retarded or in a persistent vegetative state, non-verbal,
and not approachable with any concept of death. There is no way to evaluate what they think or know of their medical condition or impending death, but the staff often have a very difficult time dealing with this situation, coping with the compound grief. The job stress and the staff turnover are problems at this facility (as they are at other healthcare institutions).

Numerous healthcare facilities have on-going peer support or grief management programs to assist staff in dealing with grief and other forms of job stress. A major local medical center has a Peer Support Program for grief and other issues. The staff at that hospital feel that their program is successful, but this is based on anecdotal reports/information, as there has been no systematic evaluation of the program.

To understand more fully the factors that influence a healthcare provider’s ability to cope effectively with compound grief will aid in the development of a more effective program to assist them in coping, to develop the skills to withstand and resolve the grief. It will allow one to develop a program that targets those elements.
amenable to intervention that will help the staff in this situation.

While there has been substantial research with nurses and compound grief in oncology units, ICU's, and some pediatric settings (i.e. pediatric oncology), this researcher found no studies in a general pediatric sub-acute setting involving as subjects registered nurses (RN's), licensed vocational nurses (LVN's) (grouped together as licensed nurses (LN's) for the purposes of this study) certified nursing assistants (CNA's), and respiratory care practitioners (RCP's, commonly known as respiratory therapists). This research adds a new dimension to an existing knowledge base.

The specific research problem here considered was to identify factors that affect healthcare providers' ability to cope with compound grief in a pediatric sub-acute facility.
CHAPTER TWO
LITERATURE REVIEW

Despite a long history of debate and a significant body of knowledge, the ambiguity surrounding the concept of grief is staggering. There is no consensus as to a concrete definition of the concept of grief, symptomology associated with the phenomenon, delineation of normal from pathological grief, or even if terms such as "pathological" are appropriate in the description (Wolfelt, 1991).

The phenomenon of grief was described by Freud (1915) as a process of gradual withdrawal of the energy that ties the bereaved individual to the deceased or lost object. Eliot (1932; cited by Jacob, 1993), an American sociologist, pioneered the empirical study of grief. He described typical reactions to grief, as well as successful and unsuccessful patterns of recovery. Building on this growing body of knowledge, Fulconer (1942; cited by Jacob, 1993) was the first to describe grief in stages. This model defined stages beginning with shock and ending with re-patterning, in which the individual has ideally established a new and stable way of life.
Lindeman's (1944) classic study of survivors of the Coconut Grove fire in Boston described normal grief as having both psychological and somatic dimensions. He reported that the signs of acute grief are universally experienced, occurring as waves of discomfort. He delineated the symptomology of the grief experience, in which common responses include: lack of concentration, hostility, guilt, preoccupation with envisioning the deceased, increased social isolation, emptiness, and sense of living in a dream. Somatic symptoms included fatigue, tightness in the throat, shortness of breath, and frequent sighing. He believed that people recover from grief in 6-8 weeks. Although his list of symptoms is basically valid, his time frame for recovery is in sharp conflict with the current notion that the process of grief resolution must be measured in years rather than weeks (Cowles and Rodgers, 1991; Jacob, 1993), and may possibly be a lifelong process (Moules, 1998).

The death and dying movement of the 1960's and the hospice movement of the 1970's shifted focus to the needs of the dying, grieving families, and societal attitudes toward death. Kubler-Ross's (1969) work identified
distinct stages of dying and served as a focus for understanding grief. She developed an elaborated stage-model of grief, describing the grieving process as progressing through denial, anger, bargaining, depression, and acceptance. Though useful to some degree and frequently cited, this stage model has been criticized as being too narrow and rigid in that it does not fully emphasize the dynamic dimension of the grieving process (Attig, 1991; Saunders and Valente, 1994; Moules, 1998), which in turn encourages the pathologizing of individuals not in synch with the stages (Moules, 1998). During this period attention to the needs of the caregivers was being extended to include the grief of the healthcare providers, primarily nurses.

Averill (1968) divided the types of grief into six major variations depending on the frequency, intensity, and duration of symptoms: normal, exaggerated, abbreviated, inhibited, anticipatory and delayed. Jacob (1993), in her review of the literature on grief, found a host of additional qualifiers of the term/process: abnormal, healthy, unhealthy, disenfranchised, prolonged, chronic, resolved, unresolved, complicated, acute, dysfunctional,
early, pathological, morbid, and traumatic. She notes that, although they are based on some ill-defined concept of normal, there is no consensus exactly what these terms mean nor how they are differentiated, with most distinctions being very subjective based again on frequency, intensity and duration of symptoms. Wofelt (1991), recognizing the powerful effect that labels can have on the patient and the provision of care, advises for the abolition of all grief qualifiers except uncomplicated or complicated grief. He notes that the terms are used too often by caregivers without a full understanding of the mourner's experience and instead of clarifying the grief, it often results in distance being created in the helping relationship: "Well, the person is having a pathological response so there is really isn't anything I can do for them." By framing the grief response as "pathological", the helper may feel incompetent to help and justified in doing nothing; those most in need of help are then abandoned. When the grief response is reframed as "complicated", the helper may still feel that s/he has the tools and knowledge to help; what is "complicated" can be made "uncomplicated".
The ambiguity of these concepts is also reflected in the nursing literature, in spite of the increasing frequency with which nurses are required to deal with grieving patients and families, and the mounting grief that they themselves experience. In an attempt to clarify this issue, Cowles and Rodgers (1991) conducted a content analysis of the English language literature in the fields of nursing and medicine published during the years 1985-1988. It was their intent to systematically identify a definition of the concept of grief as it has been used in the most current nursing and medical literature. Their initial population was every article in Index Medicus and International Nursing Index listed under the headings "grief" and "bereavement". The final sample was comprised of 74 randomly selected articles (approximately 20%): 44 selected from the medical literature, 30 obtained from the nursing journals. Analysis proceeded using phrases and themes as the units of analysis.

The researchers found the concept of grief to cover a wide range of experiences and responses. Rarely was an actual definition of "grief" provided; most authors discussed grief in regard to common symptoms. In spite of
this, Cowles and Rodgers were able to identify the predominant characteristics of the concept, as follows:

1. Dynamic - This attribute refers to the observation that grief does not present itself in a rigid, linear progression of thoughts, emotions or behaviors. Although there are identifiable “phases”, an individual is thought to move continually across all of these throughout the grief experience.

2. Process - The grief experience is a process to be worked through, clusters or phases of activity rather than as a state of being. Authors varied in their conclusions as to how long a period is required to complete the grief work, with time frames ranging from six months to two or more years. They recognized the beginnings of a trend toward the concept that in some respects grief work may be a lifelong process.

3. Individualized - The general consensus of the authors was that the grief experience is a highly variable phenomenon among individuals. This is due to a myriad of variables, including the
nature of the loss, presence of a support system, the grieving individual’s life experience/previous experience with loss, and cultural and religious background.

4. Pervasive - While highly individualized, the grief experience is considered to be pervasive, potentially affecting every aspect of a person’s existence: physical, social, cognitive, affective, behavioral, and spiritual.

5. Normative - In spite of the individualized nature and variability of the grief experience, there was a formidable effort on the part of the authors to identify “normal” grief (AKA, healthy grief, uncomplicated grief) – that is, the standard, expected response. The authors agree that the boundaries of “normal grief” are socially and culturally defined, but there was a clear consensus that there are limits to grief, beyond which it becomes unacceptable, inappropriate, and a possible indicator of underlying or associated psychopathology.
Jacob (1993) conducted a similar concept analysis of the grief literature of the 1970’s and 1980’s, with the goal of identifying the antecedents, attributes, referents, and intervening variables of the grief experience. Though unclear as to how she sampled the abundant literature of the period, her conclusions regarding the characteristics of grief were virtually identical to those of Cowles and Rodgers (1991). From these conclusions, she defines grief as, “[A] normal, dynamic, individualized process which pervades every aspect (physical, emotional, social, spiritual) of persons experiencing the loss of a significant other.” Though basically sound, Jacob unjustifiably limits her definition of grief to the loss of a significant other. As Cowles and Rodgers (1991) point out in their literature review, the grief response can be elicited by any of a number of significant losses, including those associated with divorce, chronic illness and disability, death of a companion animal, and destruction of one’s home or possessions. Jacob’s definition of grief would be more accurate and more widely applicable if the last four words were simply omitted.
Saunders and Valente (1994) offer a task-based model of bereavement based on their own clinical experience, literature review, and personal inventories provided by over 300 nurses. Including a wide range of activities that survivors accomplish over time, they identify the main task categories as:

1. **Finding meaning** - One must make sense of the death. This may be a simple task (as with an expected, dignified and "good" death of a terminally-ill patient), or a complicated task (as with an untimely or preventable death, suicide, or questions of adequate treatment).

2. **Restoring and maintaining integrity** - This involves continuing the caregivers' personal and professional integrity, wholeness, and self-esteem.

3. **Managing affect** - This involves responding to the variety of feelings (including sadness, anger, anxiety and crying) that are commonly associated with grief. This is complicated by the need to balance personal and professional attitudes, as well as attitudes of peers.
4. Realigning relationships - This involves the mending or reaffirmation of relationships that may have been affected by the patient's death. This is especially important if it was a difficult or untimely death, or if there were disputes or staff disagreements regarding patient care, treatments, etc.

They note that numerous factors influence the intensity of work required to complete these tasks, including: circumstances surrounding the death, developmental age of the bereaved, both personal and professional development; relationship issues, including the type, quality, closeness, importance and intensity of the relationship; and stigma, shame and/or disgrace resulting from social disapproval of a diagnosis, conflict over the death, or mode of death.

There is an entire body of research relating to grief and stress. Holmes and Rahe recognized this with the development of their Social Readjustment Rating Scale (1967), which ranks stressors according to their impact on one's life. They list the death of a spouse as the most stressful life event, assigning this experience 100 "life
change units (LCU's); death of a close family member rates 63 LCU's, and death of a close friend rates 37 LCU's on this scale.

Arnette (1996) documented the physiological effects of the grief experience. Empirically measurable and verifiable, the perception of an environmental event as stressful results in a number of changes in the human body, including increased activation of the sympathetic nervous system (increased adrenalin, heart rate, blood pressure); the classic "fight or flight" response, and a negative affect on immune system function. He concludes that the grief experience is physiologically measurable and virtually identical in these respects to the human body's response to stress. Further, chronic grief can have seriously detrimental effects to those persons whose health is already compromised by pre-existing medical conditions (e.g., hypertension, heart disease, arteriosclerosis, cancer, HIV or AIDS).

Davidson and Jackson (1985) compare results of "cumulative trauma in nursing" (i.e., repeated exposure to physical suffering, death and disfigurement) to the post-traumatic stress reaction identified in combat veterans.
They note that “maladaptive coping to nursing trauma” can result in a litany of symptoms similar to those suffering from PTSD: anxiety, memory difficulties, poor impulse control, de-humanization, violent outbursts, emotional withdrawal and “numbing”, along with the dreams and vivid flashbacks, increased startle response and survivors guilt.

Emery (1993) conducted a study of 155 pediatric oncology nurses, randomly selected members of the Association of Pediatric Oncology Nurses. Each nurse completed the Spielberger State-Trait Anxiety Inventory (SSTAI) and the Pediatric Oncology Nurse Stressor Questionnaire (PONSQ). The participants reported without equivocation that their greatest source of stress was the relapse or sudden death of a favorite patient. Comparing the results of the SSTAI with statistics for white-collar working women (as Speilberger did in developing the Inventory), the participants reported no more trait anxiety (anxiety related to a personality tendency toward this condition) or state anxiety (anxiety related to the present situation) than the reference group. However, the PONSQ indicates that pediatric oncology nursing is a very stressful profession.
Bond (1994) conducted a similar study of 92 randomly selected members of the Association of Pediatric Oncology Nurses using the Stressor Scale for Pediatric Oncology Nurses (SSPON). In this study, the items rated most stressful by the participants were, "Watching a patient suffer and not being able to do anything about it," with a rating of 89, followed closely by, "When a favorite patient dies," rated 88. Comparing total scale scores, Bond found no significant differences in response between nurses with less than 5 years experience in pediatric oncology (n=44) from those with greater than 5 years experience (n=48).

Stress in the nursing profession is of importance because of its association with job burnout and the accompanying decline in quality of patient care, and the increasing rate of job turnover. Oehler and Davidson (1993) define burnout as, "[A] syndrome of physical and emotional exhaustion involving the development of negative job attitudes and loss of concern and feelings for clients." In a study of 121 pediatric nurses, they measured levels of job stress, anxiety, experience, social support, and burnout in acute and non-acute care settings. Their analysis revealed that job stress was the strongest
significant predictor of burnout, followed by state anxiety, low co-worker support, trait anxiety, and experience on the unit. They do note that pediatric nurses are of particular concern because: (1) of the degree of dependence of these patients, and (2) because of the special significance of sick children and infants to their parents and in society as a whole.

In their discussion of nursing stress and post-traumatic stress reaction, Davidson and Jackson (1985) relate burn-out to the experience of cumulative trauma in the nurses' experience. They feel that full recovery from burn-out will be better understood as more is known about the long-term symptoms and consequences of trauma.

In their study of the relationship between grief and burn-out among oncology nurses, Feldstein and Gemma (1995) state that compounded grief is a powerful factor contributing to resignations and turnover. They conclude, "[T]hat what clinicians and lay persons alike describe as "burnout" is actually compounded grief." Hinds, et al. (1994) report identical findings from a study on the effects of a grief workshop on grief symptoms and perceived stress in a group of oncology nurses. However, this is not
meant to imply that compound grief is the only factor in
generating job burn-out and turnover in the nursing
profession, as other studies have identified other factors,
personal and professional, that contribute to this
phenomenon (McElroy, 1982; Yasko, 1983).

Grief and bereavement sensu strictu have been studied
in a number nursing settings, utilizing various research
tools and methodologies. Eakes (1991) conducted a study of
hospice nurses to investigate how they effectively resolve
their grief while dealing with multiple deaths. This
qualitative study consisted of the systematic analysis of 5
sets of interviews (5 subjects, 2 interviews with each
subject) to identify the recurring themes that are central
to the nurses' ability to achieve resolution of their
grief. Eakes identified the following themes:

1. Establishment of a collaborative relationship
   with the patient, with a careful balance between
   over- and under-involvement with the patient and
   family.

2. Shift of focus from curative to palliative care
goals, and assisting the patient in accepting
death as a fact of life.
3. The importance of being comfortable in open and honest airing of their feelings, with patients/family and peers.

4. The importance of maintenance and use of solid support systems, including peers, spouses and other family members.

5. The importance of achieving a sense of closure to the relationships with dying patients and their families. This is often a personal visit with the family, not to be confused with the bereavement follow-up common as part of hospice-agency practice.

In a similar study, Rittman, et al. (1997) analyzed six narratives written by experienced oncology nurses, professionals considered by their peers and supervisors to have a high degree of expertise in their field. The questions guiding the study were straightforward and well laid out: 1) What skills do nurses use in providing care to dying patients and their families? 2) What do nurses experience in caring for dying patients? 3) What meanings sustain nurses while working with dying patients? The
hermeneutic method of analysis was used to gain an understanding of the phenomenon being studied.

Their findings included the same elements as Eakes' earlier study, with some important differences. The nurses interviewed all recognized the uniqueness and individuality of each patient, circumstance, and the unique nurse-patient relationships that develop. This ability to develop different levels of intensity in nurse-patient relationships is critical in managing the emotional demands of their work. Rittman also reports the importance to the subjects of helping the patient maintain or preserve hope, and the importance of privacy in dying for the patient and family. It is interesting to note that Rittman, et al. make no mention of the importance of support systems or airing one's feelings as part of the repertoire of the professionals' coping tools.

Although the size of the data set was quite small, an important strength of this study was the use of a research team to evaluate the narratives. It was felt that the use of a team would provide "for richer interpretive analysis of the data." They felt that nurses were best suited to
appreciate the subtleties of the narratives and so used a team bridging the nursing hierarchy.

The quantitative study of professional healthcare providers' grief has been hampered by the lack of suitable measurement instruments. The most commonly encountered instrument in the literature is the shortened version of the Grief Experience Inventory (Hinds et al., 1994; Feldstein and Gemma, 1995). The Grief Experience Inventory (GEI) Sanders, Mauger, and Strong, 1985) is a 135-item dichotomous (yes/no) questionnaire that yields scores on nine scales, three validity scales and six clinical scales. The validity scales assess test-taking attitudes, include Denial, Social Desirability, and Atypical Responses. The clinical scales, which assess the multidimensional aspects of the grief experience, include Despair, Anger/Hostility, Social Isolation, Loss of Control and Somatization. A shortened 102-item version was developed by the authors, tested over several years, and found to be valid and reliable.

Feldstein and Gemma (1995) used the shortened GEI in their study of burn-out among oncology nurses. This inventory was combined with a demographic questionnaire to
determine what other factors (i.e., personal, professional, and supportive) might have influenced the respondents' grief experience. The purpose of this study was to compare the overall grief experience as well as measurements on the various sub-scales between those nurses who stayed (Stayers) and those who left (Leavers) their positions. Nurses who resigned their positions were contacted via phone and mail; a total of 50 sets of completed questionnaires were returned. Research indicated that there was no significant difference in overall level of grief between Stayers and Leavers. Stayers were high on Despair, Social Isolation, and Somatization, low on Loss of Control and Death Anxiety; Leavers were high on Despair, Social Isolation, and Somatization, low on Loss of Control, Anger/Hostility, and Death Anxiety.

Hinds, et al. (1994) conducted a study to determine the impact of a grief workshop on grief symptoms and perceived stress in 2 groups of pediatric oncology nurses who differed in years of experience in the specialty. They used the shortened Grief Experience Inventory (GEI), combined with the Miller Behavior Style Scale (MBSS) and the Perceived Stress Scale (PSS) in a pretest-posttest
experimental design. Twenty-two nurses completed the workshop and all questionnaires. The results of this study indicate a high correlation between stress and grief symptoms for both groups of nurses on all GEI sub-scales except death anxiety. Interestingly, both groups scored higher after the workshop on the sub-scales for Despair, Social Isolation, and Somatization; declines on the other sub-scales was fairly small. This lack of positive change may be attributable to an ineffective intervention. However, the expectation of significant change in grief symptoms in such a short period of time may be conceptually inconsistent with the understanding of grief/grieving as a process.

Lev, Munro, and McCorkle (1993) conducted a study with the intent of developing a more effective, theoretically-based instrument to measure bereavement. Starting with the GEI, they revised the tool according to Parkes' (1972) framework. Twenty-two items were selected from the original 135-item GEI, representing the 4 areas of the grief experience conceptualized by Parkes: existential concerns, depression, tension and guilt, physical distress. Variability of response to each item in the Revised Grief
Experience Inventory (RGEI) was increased by changing from a dichotomous response (yes/no) of the original GEI to a 6-point Likert scale, ranging from strong disagreement to strong agreement. Four hundred and eighteen hospice and oncology nurses completed the RGEI and a demographic questionnaire. The results of the study were generally consistent with previous findings of the differences in bereavement between men and women, the closeness of the relationship with the deceased as predictive of the intensity of the grief reaction, grief reaction and time since loss, etc. More important, however, is that the results of the study found the RGEI to be a concise, valid, and reliable measure sensitive to the grief experience (see below).
CHAPTER THREE

METHODS

The purpose of this study was: (1) to evaluate the level of grief experienced by healthcare providers in a pediatric subacute facility, (2) to compare the levels of grief between different groups of healthcare providers (Certified Nurses’ Aides, Licensed Vocational Nurses, Registered Nurses, and Respiratory Care Practitioners), and (3) to describe the personality/demographic factors that influence a healthcare provider’s ability to cope effectively with compound grief.

The research followed a descriptive, correlational design, using a combination of 2 surveys, one for demographic variables, another to measure the level of grief experienced. This approach has been used very effectively in a number of studies.

The study population implicit in this question is the entire group of healthcare providers in pediatric subacute facilities; there are approximately 12 of these in the state of California. For the purposes of this study, a sub-population was selected based on the following criteria: (1) this survey included providers at only one of
these facilities (Totally Kids Specialty Healthcare), and (2) the study included only those providers in the four disciplines already enumerated (CNA's, LVN's, RN's, RCP's) who provide hands-on day-to-day care; there were no administrators, supervisors, or managers included in this study. Totally Kids Specialty Healthcare was selected because it is geographically close and has a sufficient employee base to provide statistically meaningful results. The inclusion/exclusion of specific disciplines was determined by the number of professionals in each specific group - i.e., there were not enough physical, occupational or speech therapists to provide meaningful results, therefore they were not included in this study. This plan included a maximum sample population of approximately 148 individuals: 50 CNA's, 52 LVN's, 10 RN's, and 36 RCP's.

The dependent variables were the levels of grief experienced as measured by the Revised Grief Experience Inventory (RGEI; see APPENDIX A) developed by Sanders et al. (1985), and revised by Lev et al. (1993). With Lev's permission, the RGEI was modified slightly to meet the needs of this study (see APPENDIX B). The RGEI is a 22-item questionnaire that assesses 4 areas of the grief
experience as conceptualized by Parkes (1972): existential concerns; depression, tension and guilt, physical distress. Statements of attitude or feeling pertaining to these areas are rated by the subjects on a 6-point Likert scale, ranging from strong disagreement to strong agreement. Use of this instrument results in 5 dependent variables: an overall grief experience measurement and separate measurements for each of the 4 sub-scales.

Independent variables fell into 2 major clusters: personal variables and professional/educational variables (see APPENDIX C). Personal variables included information such as age, gender, ethnicity, religious preference/level of spiritual involvement, marital status/living situation, support system, and history of recent loss(es). Professional/educational variables included current position held, length of time in healthcare, length of time at TKSH, length of time in current position, years of education, certificates/degrees held, and day/night shift.
CHAPTER FOUR

REVISED GRIEF EXPERIENCE INVENTORY

The RGEI was developed from the GEI with the intention of developing a grief measurement instrument based on a firm theoretical foundation; the original GEI was not developed from a theoretical perspective, but from an attempt to quantify data from individual interviews. Twenty-two items from the original 135-item survey were selected as representative of the 4 areas of grief as conceptualized in the Parkes framework (Lev et al., 1993). Content validity was established by a group of experts: doctorate level nurses with expertise in oncology nursing, and clinical specialists in 2 hospice settings (Lev et al., 1993). Factor analysis was used to test the construct validity of the RGEI; that is, the extent to which the internal structure this instrument matched the Parkes conceptualization of grief. A four factor solution, matching Parkes' model, emerged accounting for 57.7% of the variance: factor 1, existential concerns; factor 2, depression; factor 3, tension and guilt; factor 4, physical distress. The reliability of the four factors were: factor 1, six items (alpha = 0.87); factor 2, six items (alpha =
0.80); factor 3, three items (alpha = 0.72); factor 4, seven items (alpha = 0.83) (Lev et al., 1993).

Modification of the RGEI for the purposes of this study included only minor rewording of item one. This was deemed appropriate to enhance the focus of this grief measurement instrument on the nature of the deaths experienced in a pediatric sub-acute setting.
CHAPTER FIVE
PROCEDURE

Recruitment of subjects for this study began with a letter to all employees describing the study and requesting their participation (APPENDIX D), followed by a brief presentation at the start of each shift. All staff members who agreed to participate were required to sign an Informed Consent form (APPENDIX E), indicating their knowledge of this study's purpose and procedure as well as their voluntary participation. A debriefing statement (APPENDIX F) was provided to each participant describing the study just completed, when and how to obtain results of the study if desired, and who to contact with questions or concerns pertaining to this study. Consent statements, questionnaires, and debriefing statements were distributed at that time to those wishing to participate and collected during the same shift; the debriefing statement was retained by each participant. Completion of both questionnaires (demographic and RGEI) required approximately 6-8 minutes. This researcher personally contacted 129 employees, distributed and collected all consents and questionnaires. Data collection was limited
to a period of 8 days to minimize the possibility that changing conditions at the medical facility might influence results.

All data were maintained in strict confidence and all participant responses were anonymous; as data was analyzed by group (entire staff as well as by discipline), there was no need to identify individuals. Additionally, no data were collected until this proposed study was reviewed and approved in writing by the C.S.U.S.B. Institutional Review Board (or the Dept. of Social Work Subcommittee of the C.S.U.S.B. I.R.B.) as well as TKSH administration (APPENDIX G).
CHAPTER SIX

RESULTS

Of the 129 workers that were contacted, two declined to participate and 127 sets of questionnaires were distributed; 115 sets were returned (91% return rate). Although many of the questionnaires contained some missing data or confusing responses, only two sets of questionnaires were omitted from this study as they were grossly incomplete. The following results were based on the remaining 113 sets of questionnaires (89% of total number distributed).

Univariate analysis was conducted initially to establish a baseline value for each variable, and describe the most relevant characteristics of this sample population. Means and frequencies were established, as appropriate, for all variables. These calculations were conducted on the entire sample population, as well as on the three subgroups, by discipline (Certified Nurses’ Aides, Skilled Nurses, Respiratory Care Practitioners). It was originally intended that data would be collected and comparisons made among four categories of healthcare providers: CNA’s, LVN’s, RN’s and RCP’s. However, only
nine RN's responded providing too small a sub-population for statistically reliable results. It was therefore necessary to combine RN's and LVN's into one category, licensed nurses (LN). All statistical calculations were computed using the SPSS version 10.0. The results of this univariate analysis are summarized in Tables 1 and 2; this allows easy comparison between sub-populations.

The study sample was 25.9% male (n=29) and 74.1% female (n=83). They ranged in age from 20 to 57 years, with an average age of 35.4 years. Marital status varied with 32.7% single (n=37), 45.1% married (n=51), and 22.2% separated, divorced or widowed (n=25). Of this group, 92.8% identified a support system (n=103), person(s) with whom they can talk about their work, but 27.6% reported that this is seldom or never enough support (n=29). Most respondents, 50.4%, reported "other losses" in addition to patient deaths (n=57), with 10.6% reports of multiple losses within the past year (n=12).

The study population represented significant ethnic diversity with 34.8% Caucasian (n=39), 25.0% African-American (n=28), 18.8% Hispanic (n=21), 10.7% Filipino
(n=12), 9.8% other Asian (n=11), and .9% Native American (n=1).

Expressed religious preference was quite varied, with 52.2% Protestant (n=59) (representing eight denominations, including those who identified themselves as Christians), 19.5% Catholic (n=22), 8.8% Seventh Day Adventist (n=10), .9% Buddhist (n=1), and .9% Moslem (n=1); 5.3% identified no religious preference (n=6) and 8.8% declined to respond (n=10). Level of religious involvement ranged from "not at all" (12.4%, n=14) to "very involved" (20.0%, n=22), with the majority of respondents identifying themselves as "somewhat" (38.2%, n=42) to "significantly" involved (29.1%, n=32).

The study population was 31.9% Certified Nurse’s Aids (CNA’s; n=36), 40.7% Licensed Nurses (LN’s; n=46), and 27.4% Respiratory Care Practitioners (RCP’s; n=31). Their length of employment in the healthcare field ranged from approximately 1 month to 35 years, with an average of 8.7 years. Day shift (50.9%, n=57) and night shift (49.1%, n=55) workers were nearly equal in representation. Number of patient deaths experienced in the past year by each worker ranged from 0 to 25, with an average of 2.5 patient
deaths. This is in addition to “other losses” previously identified. All employees have completed high school, 34.0% have received an AA degree (n=35), 9.7% have a BS/BA (n=10), and 3.9% have an MS/MA degree (n=4). Viewed as a 4-point Likert scale (1=high school, 2=AA degree, 3= BS/BA, 4=MS/MA), the mean education level for this population was 1.65.

Differences Among Professional Groups

The CNA’s were overwhelmingly female (88.6%, n=31), with an average age of 31.8 years in a range of 20-55 years. The LN’s were also overwhelmingly female (82.6%, n=38), with a mean age of 36.2 years in a range of 21-57 years. The RCP’s showed a somewhat different profile. This group was 54.8% male (n=17) and 45.2% female (n=14). They ranged in age from 22 to 55 years, with a mean age of 37.9 years.

Marital status of the CNA’s was 50.0% single (n=18), 36.1% married (n=13), and 13.9% separated, divorced, or widowed (n=5). Of the LN’s, 19.6% were single (n=9), 52.2% married (n=24), and 28.2% separated, divorced or widowed (n=13). RCP’s reported to be 32.3% single (n=10), 45.2%
married (n=14), and 22.6% separated or divorced (n=7).

The vast majority of respondents in all three professional groups identified a support system, person(s) that they can talk to about their work: 91.4% of CNA’s (n=32), 97.8% of LN’s (n=44), and 87.1% of RCP’s (n=27). However, a significant percentage of respondents in each group reported that this support system is seldom or never enough; 42.5% of CNA’s (n=14), 14.0% of LN’s (n=6), and 31.0% of RCP’s (n=9) reported this to be the case. Fifty percent of the CNA’s (n=18) reported “other losses” (in addition to an average of 2.6 patient deaths experienced per year), including 19.4% who reported multiple losses within the past year (n=7). Among the LN’s, 54.3% (n=25) reported “other losses” (in addition to an average of 1.7 patient deaths experienced per year), including 6.5% who reported multiple losses within the past year (n=3). Of the RCP’s, 45.2% (n=15) reported “other losses” (in addition to an average of 3.5 patient deaths experienced per year), including 6.5% who reported multiple losses within the past year (n=2).

Ethnic composition of the group of CNA’s was 25.7%
Caucasian (n=9), 42.9% African-American (n=15), 17.1% Hispanic (n=6), 2.9% Filipino (n=1), 8.6% other Asian (n=3), and 2.9% Native American (n=1); 2.8% declined to respond (n=1). The LN’s were 32.6% Caucasian (n=15), 19.6% African-American (n=9), 21.7% Hispanic (n=10), 17.4% Filipino (n=8), and 8.7% other Asian (n=4). The RCP’s as a group reported 48.4% Caucasian (n=15), 12.9% African-American (n=4), 16.1% Hispanic (n=5), 9.7% Filipino (n=3), and 12.9% other Asian (n=4).

Religious make-up of each sub-group was quite varied, and differed noticeably among sub-groups. The CNA’s included a greater percentage of Protestants (74.1%, n=23) than either the LN’s or RCP’s (48.7%, n=20, and 51.6%, n=16, respectively) and the single Moslem in the study. The LN’s included the only Buddhist.

CNAs’ level of religious/spiritual involvement ranged from “not at all” (11.4%, n=4) to “very involved” (25.7%, n=9). Of this sub-group, 62.9% identified themselves as “somewhat” (40.0%, n=14) or “significantly” involved (22.9%, n=8); mean score was 2.63 (on a 4-point Likert scale, “4” being “very involved”). LNs’ level of religious/spiritual involvement ranged from “not at all”
(15.6%, n=7) to "very involved" (17.8%, n=8); 66.7% of respondents identified themselves as "somewhat" (35.6%, n=16) or "significantly" involved (31.1%, n=14). Mean score for this group was 2.51. RCPs' level of religious/spiritual involvement ranged from "not at all" (10.0%, n=3) to "very involved" (16.7%, n=5); 73.3% of respondents identified themselves as "somewhat" (40.0%, n=12) or "significantly" involved (32.3%, n=10). Mean score for this group was 2.57.

Length of employment in healthcare for the CNA's ranged from three months to 30 years, with a mean of 7.7 years. In their current position at Totally Kids, 52.8% worked nights (n=19), 47.2% worked days (n=17). Length of employment in healthcare for the LN's ranged from one month to 35 years, with a mean of 8.8 years. In their current position at Totally Kids, 53.3% worked nights (n=24), 46.7% worked days (n=21). For the group of RCP's, length of employment in healthcare ranged from one to 35 years, with a mean of 9.6 years. In their current position at Totally Kids, 45.2% worked nights (n=14), 54.8% worked days (n=17); 1 individual shift was unidentified.
Table 1. Frequency and Percentage of Categorical Variables

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<th>Variable</th>
<th>CNA (n=36)</th>
<th>LN (n=46)</th>
<th>RCP (n=31)</th>
<th>Total Sample (n=113)</th>
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<td></td>
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<td>%</td>
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<td>RCP (n=31)</td>
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</table>

With a minimum education of high school completion for all CNA's, 12.1% had received AA degrees (n=4), 9.1% had a BS/BA (n=3), and 3.0% had an MS/MA degree (n=1). Viewed as a 4-point Likert scale (1=high school, 2=AA degree, 3=BS/BA, 4=MS/MA), the mean education level for this subgroup was 1.39. All LN's were appropriately trained and
licensed; 36.6% had an AA degree (n=15), 12.2% had a BS/BA (n=5), 2.4% had an MS/MA degree (n=1). Viewed on the same 4-point scale, the mean education level for this sub-group was 1.68. All RCP’s were also appropriately trained and licensed with a minimum of a high school education; additionally, 55.2% had an AA degree (n=16), 6.9% had a

Table 2. Means, Standard Deviations, and Minimum/Maximum of Continuous/Ratio Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>CNA</th>
<th>SN</th>
<th>RCP</th>
<th>Total Sample (n=113)</th>
</tr>
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<td>22-55</td>
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<td>8.80</td>
<td>9.60</td>
<td>8.68</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>5.79</td>
<td>6.36</td>
<td>8.47</td>
<td>6.84</td>
</tr>
<tr>
<td>Min.- &gt; Max.</td>
<td>.25-30</td>
<td>.10-35</td>
<td>1-32</td>
<td>.10-35</td>
</tr>
<tr>
<td>Yrs. at Totally Kids</td>
<td>2.07</td>
<td>3.30</td>
<td>2.70</td>
<td>2.76</td>
</tr>
<tr>
<td>Mean</td>
<td>2.07</td>
<td>3.30</td>
<td>2.70</td>
<td>2.76</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>1.94</td>
<td>2.74</td>
<td>1.82</td>
<td>2.32</td>
</tr>
<tr>
<td>Min.- &gt; Max.</td>
<td>.08-</td>
<td>.08-11</td>
<td>.08-7</td>
<td>.08-11</td>
</tr>
<tr>
<td>Yrs. Current Position</td>
<td>1.86</td>
<td>2.47</td>
<td>2.32</td>
<td>2.25</td>
</tr>
<tr>
<td>Mean</td>
<td>1.86</td>
<td>2.47</td>
<td>2.32</td>
<td>2.25</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>1.76</td>
<td>1.92</td>
<td>1.66</td>
<td>1.80</td>
</tr>
<tr>
<td>Min.- &gt; Max.</td>
<td>.08-6.17</td>
<td>.08-7.42</td>
<td>.08-6.00</td>
<td>.08-6.00</td>
</tr>
<tr>
<td>Grief Score</td>
<td>55.15</td>
<td>47.77</td>
<td>48.61</td>
<td>50.31</td>
</tr>
<tr>
<td>Mean</td>
<td>55.15</td>
<td>47.77</td>
<td>48.61</td>
<td>50.31</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>24.25</td>
<td>15.82</td>
<td>22.86</td>
<td>20.86</td>
</tr>
<tr>
<td>Min.- &gt; Max.</td>
<td>22-121</td>
<td>22-86</td>
<td>22-97</td>
<td>22-121</td>
</tr>
</tbody>
</table>
BS/BA (n=2), 6.9% had an MS/MA degree (n=2). Viewed on the same 4-point scale, the mean education level for this group was 1.90.

Mean overall grief score for the CNA sub-population was 55.15 (range: 22-121), 47.77 (range: 22-86) for the SN sub-population, and 48.61 (range: 22-97) for the RCP sub-population. Mean overall grief score for the study population as a whole was 50.31 (range: 22-121).

Bivariate correlations were calculated to determine possible relevant relationships between variables; all results were evaluated at \( p \leq 0.05 \). This provided information on the relationships among demographic variables.

Differences in marital status among the subgroups (based on current position: CNA, LN, or RCP) were striking; however, a chi square test did not show this to be significant at .05 level. A chi square test of the differences in level of education among these subgroups did demonstrate these differences to be significant (\( p = .013 \)). T-tests comparing mean education levels between these groups pin-pointed the significant difference as that difference in mean education between the CNA's and the RCP's (\( t = -2.463 \), df=60, \( p = .017 \)).
The correlation matrix also provided information regarding relationships between these independent variables and the overall grief level (dependent variable), and helped focus attention on those variables/relationships that warranted closer examination. Four variables showed a statistically significant correlation with the overall grief measurement: 1) inadequate support system ($r=-.407, p=.000$), 2) less time in their current position ($r=-.221, p=.023$), 3) having other losses ($r=.210, p=.028$), and 4) low level of religious involvement ($r=-.197, p=.041$). Several of the variables showed a significant correlation with at least one of the grief sub-scales, but not with the overall grief measurement. "Age" showed a negative correlation with the depression sub-scale ($r=-.209, p=.036$), but no statistically significant correlation in its relationship with the overall grief measurement ($r=-.154, p=.126$). Likewise, "length of employment at TK" was correlated with the physical symptoms sub-scale ($r=-.235, p=.015$), "number of patient deaths this year" was correlated with the guilt sub-scale ($r=-.211, p=.035$), as was "years in healthcare" correlated with the guilt sub-scale ($r=-.188, p=.050$), but none of these variables showed significance when correlated
with the overall grief measurement. However, when recoded from continuous data into ordinal categories (0-3 years vs. 4 or more years), "years in healthcare" demonstrated a marked relationship with the overall grief score ($t=2.688$, $df=102$, $p=.008$). This recode was prompted by a close examination of the variable frequencies which indicated the presence of a potentially significant shift in coping skills/grief score in this time period. It is unusual, however, that recoding data to a lower level of measurement would enhance the visibility of a correlation, and it is unclear on the basis of this study why it occurred in this instance. Further research will be required to determine what is happening during this period at 3-4 years into the health care provider's professional development to account for this change.

T-tests were completed to compare the mean grief scores between sub-categories of the sample population. All three disciplines (CNA, LN, and RCP) were compared with each other, as was gender (male vs. female), shift (day vs. night), years in healthcare (0-3 years vs. 4 years or more), and the four largest ethnic groups represented (Caucasian, African-American, Hispanic, and Asian). None
of these t-tests showed significant differences in the mean

grief measurements, with the exception of "years in

healthcare". Due to possible reasons discussed below, it

appears that those in healthcare 4 or more years have

significantly less grief symptomology that those in

healthcare 3 years or less.

The correlation matrix pointed to a number of

significant relationships between independent variables,

e.g. age and marital status \( (r=0.442, p=0.000) \), age and

number of children \( (r=0.445, p=0.000) \), age and time in

current position \( (r=0.302, p=0.002) \), age and education level

\( (r=0.268, p=0.010) \), etc. These significant correlations all

surrounding age validate the importance of this variable.

It does, however, demonstrate only a minor direct effect on

the grief score. The effect of that variable (age) on the

grief experience is better explained or subsumed in a

different correlation. That is to say, age correlates

strongly with years in healthcare and time in current

position, and both of these latter variables correlate with

grief, as does age in a very weak fashion. Therefore,

rather than focus on age, a relatively unimportant variable

in and of itself, this research targeted time in current
position and its effect on the experience of grief, recognizing that the effects of age are included in this relationship.

Several of the variables are related in a fashion and overlap somewhat in meaning and implication, i.e. "years in healthcare", "time at TK", and "time in current position", yet only "time in current position" showed an immediate and significant correlation with the overall grief score ($r=-.221, p=.023$). There are several possible explanations for this. Years in healthcare may have been spent in jobs that do not require providing hands-on care or include dealing with or encountering death and dying. Time at TK may have been spent in positions other than that currently held by the staff included in this research, positions more insulated from the daily reality of the medically fragile child. Use of the variable "time in current position" eliminates some of these ambiguities as it is by definition only those employees providing direct daily hands-on care.

Review of the frequencies of variable measurements revealed an unexpectedly high number of grief scores of 22, the lowest possible measurement ($n=6$). It was unclear if in fact there are 6 respondents experiencing no grief.
symptoms or if some respondents simply marked all 1's on
the questionnaire in order to be done quickly. The concern
was that these figures might skew the results and indicate
an erroneously low grief measurement, demonstrating phantom
relationships or masking correlations that do exist. In
order to test this hypothesis, a 2nd correlation matrix was
developed excluding these 6 questionable cases (n=107).
Comparison of these 2 correlation matrices, one including
all cases (n=113 and n=107, respectively) showed only very
minor differences in correlation (r) or significance
calculations; the new matrix showed no new significant
relationships nor masked significant correlations
previously identified. Therefore, without compelling
reason to exclude data, these 6 cases were retained and
included in all calculations.

Based on significant relationships identified in
the correlation matrix, 4 independent variables were
selected to be included in a stepwise multiple regression
with the grief measurement as the dependent variable: 1)
Level of religious involvement, 2) Other losses, 3) Months
in current position, and 4) Quality of support system
(“enough support?”). This allowed closer examination of
the relationship between the predictor and criterion variables providing an assessment of the relative value of different predictor variables and their combined effect in accounting for variation in the criterion variable. The value of the multiple regression is that it takes into consideration the fact that the predictor variables are not only correlated with the criterion variable, but are correlated to some degree with each other. The prediction power of one variable may duplicate the prediction power within another variable, therefore the combined effect of the four variables ($R^2$) is not the same as the sum of the individual $r^2$'s. The combined effect of these variables accounted for 25.1% of the grief score in this model ($F=7.771$, $p=.0005$). (See Table 3.)
<table>
<thead>
<tr>
<th>Model</th>
<th>R</th>
<th>R²</th>
<th>R² Change</th>
<th>B</th>
<th>β</th>
<th>F</th>
<th>Sig. F Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.203</td>
<td>.041</td>
<td>.041</td>
<td>-4.379</td>
<td>-.203</td>
<td>4.112</td>
<td>.045</td>
</tr>
<tr>
<td>2</td>
<td>.325</td>
<td>.106</td>
<td>.065</td>
<td>7.782</td>
<td>.254</td>
<td>6.853</td>
<td>.010</td>
</tr>
<tr>
<td>3</td>
<td>.390</td>
<td>.152</td>
<td>.046</td>
<td>-.208</td>
<td>-.219</td>
<td>5.126</td>
<td>.026</td>
</tr>
<tr>
<td>4</td>
<td>.501</td>
<td>.251</td>
<td>.099</td>
<td>-7.307</td>
<td>-.332</td>
<td>12.244</td>
<td>.001</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Model</th>
<th>Mean Sq.</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>2643.736</td>
<td>.771</td>
<td>.000</td>
</tr>
<tr>
<td>Residual</td>
<td>340.192</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Key for predictor variables in each model, with Grief as criterion variable:
1. (Constant), level of religious involvement
2. (Constant), level of religious involvement, other losses
3. (Constant), level of religious involvement, other losses, years in current position
4. (Constant), level of religious involvement, other losses, years in current position, level of support system
CHAPTER SEVEN

DISCUSSION

There are several possible explanations for the correlation of the variable "time in current position" with the grief experience; that is, the longer an employee is in their position, the lower their grief score. Possible explanations include: 1) it is a self-selecting process in that those who cannot cope, leave their position, facility, or field of employment (the literature often calls it stress or job burn-out), and 2) the longer one is in their position, the better one develops effective coping skills. This last possibility is further supported by the t-test comparing mean grief scores of those in healthcare 3 years or less with those in healthcare 4 years or more. The statistically significant difference in mean grief scores (t=2.688, df=102, p=.008) indicates that the longer one works in the healthcare field, the greater one’s ability to withstand the effects of grief. It is clear from these results that a low level of religious/spiritual involvement and high grief symptomology grief are correlated (r=-.197, p=.041). What is unclear from these data is whether or not a particular religious/spiritual preference
provides greater buffer against the experience of grief. The original data included categories of 12 specific religious preferences, "other", and "none"; however, none of these categories were large enough for comparison leading to statistically reliable results. Recoding of the available data into sensible groupings left Protestant, Catholic (both Judeo-Christian belief systems; n=59 and 22, respectively), "other" (n=16), "none" (n=6); analysis based on these groupings would be meaningless, neither reliable nor valid.

Low level of social support felt by the individual showed the strongest correlation with higher grief experience (r=.407, p=.000). It is beyond the scope of this project to attempt a definitive explanation or description of the respondents’ support systems, or how this might change over time, however important this information might be in formulating effective interventions. It is sufficient for present purposes to simply identify that a lower level of social support has a significant correlation with an individual’s greater experience of grief. Possible measures that might be
undertaken by the facility to enhance employees' sense of support will be discussed below.

The results of the multiple regression are interesting in that they clearly demonstrate that the combined effect of the 4 variables ($R^2=.251$) is not simply the sum of the individual predictor values ($r^2=.297$). The 4 variables are correlated with each other in some fashion and duplicate predictor power to some extent as related to the grief measurement. The support system variable, in particular, appears to have a statistically significant relationship with "other losses" ($r=-.239$, sig. = .014), a variable representing loss of support to the individual. This same variable approaches significance in its correlation with "level of religious involvement" ($r=.189$, sig. = .056), a source of support and important coping mechanism for some individuals.

An unexpected outcome of this study was that it became an educational experience for many participating staff members. During the face-to-face interaction at the time of collection of the surveys, many staff members made comments or observations such as, "I never connected my irritability [or lack of energy, focus, listlessness, etc.]
with my work here. I've just felt so lost since Alan died." All of these were taken as opportunities for the researcher/social worker to work with staff regarding these grief issues.
CHAPTER EIGHT
IMPLICATIONS FOR PRACTICE AND FURTHER RESEARCH

In order to buffer against the negative effects of compound or complicated grief, one must first identify those factors that correlate with the grief experience. Only then can one develop interventions to counter-act or minimize those factors that contribute to the grief and maximize or support those factors that provide the buffer or enhance coping mechanisms. This research has identified 4 variables that correlate with the grief experience: having other losses and low level of religious involvement are associated with increased grief, while longer time in current position and having an adequate support system are associated with reduced grief. Of these, some are amenable to social work intervention, some not. For the purposes of this research and the healthcare providers at Totally Kids, appropriate social work intervention may entail branching off in several directions simultaneously.

"Other losses", those adverse events that occur in one's personal life, is not in itself controllable either on or off the job. As the old saying goes, "Life is what happens while we have other plans." However, positive
proactive social work intervention (discussed below) may affect how the worker copes with these other losses both on and off the job.

"Level of religious/spiritual involvement" is typically a very personal issue, and not traditionally the arena of the social worker. However, it is now widely recognized that the strength of spiritual belief can be a powerful influence in one’s ability to cope with life’s adverse events, especially those existential questions of life and death. Given the personal nature of this realm, the legal and ethical nature of resident’s and staff rights, and the variety of religious/spiritual beliefs, movement in the development of supportive policies and programs in this area is deliberate and loaded with potential pitfalls. However, there are a number of options that are possible to increase the pastoral presence at the facility. TK has a long-standing practice of memorial services after the death of a child, and may consider monthly non-denominational religious services at the facility. Attendance is voluntary at the memorial services and would be voluntary at any other religious service or event. It may also be feasible to invite a variety of
clergy to visit the facility on a regular basis to be available to staff and families of residents.

"Time in current position" and "level of support system" may be amenable to social work intervention in a number of ways. There are a number of different types of programs that may be beneficial in enhancing the staff members' support system and increasing their longevity in their current position. Staff education and support groups are obvious possibilities with a myriad of variations, as well as other measures to enhance staff cohesiveness and teamwork. A large local medical center has a Peer Support Program that is believed to be effective, but this effectiveness has never been measured in any systematic way. Programs that enhance the work-related support system of the workers may have several positive effects: 1) reduce the adverse affect of grief on the job, 2) reduce burn-out, 3) reduce grief and stress from those "other losses" that occur outside of work, and 4) increase employee retention. Other strategies may be implemented at the administrative level to enhance longevity on the job (enhanced wage and benefit packages, new forms of staff recognition, etc.).
The shape and form of programs to be developed is the next major question. To tackle this, it would be useful to know more about the support systems of the staff members and their beliefs in this area. What does it mean to the individual to be fully supported, or adequately supported? What constitutes a good support system? How do they envision a supportive work environment? This information may be forthcoming from current employees as well as from those staff members that are leaving TK. Why staff members leave their employment at TK may be quite revealing, but as of now there is no formal system of exit interviews of employees upon discharge. If the administration is serious in their efforts to reduce the adverse effects of grief and stress and enhance employee retention, these questions must be addressed. Another avenue of research is to systematically evaluate the effectiveness of support programs, staff education etc. at other medical facilities as they relate to the question of grief management. These are but a few of the questions for further research.

Other directions of study would be to expand this research to include staff at other similar facilities, and also to examine the level of grief experienced over time,
that is, a longitudinal study conducted in the same facility with the same population. Data collection for this current study was conducted at a time when there had been no deaths at the facility for approximately 8 months. However, it is not uncommon to experience 4 deaths in 3 months. Data collection at regular intervals (every 6-8 months) for 1-2 years may identify these fluctuations and reveal significant information that will benefit program development and staff.

Another avenue of research to explore would be the process of professional development in the formative of healthcare providers, that period at three to four years into their career. What is happening in that period that results in increased coping skills in dealing with their grief?

The value of this completed research can achieve fruition only when information collected is utilized and appropriate measures taken to assist the healthcare providers in completing their tasks with a minimum of stress and grief. This work is the first step to that end.
Below are a series of general statements. You are to indicate how much you agree or disagree with them. Be as honest as possible. Remember, there are no right or wrong answers to these questions.

Read each item and decide quickly how you feel about it; then circle the number of the item that best describes your feelings. Put down your first impressions. Please answer every item.

<table>
<thead>
<tr>
<th></th>
<th>agreement</th>
<th>disagreement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>slight</td>
<td>moderate</td>
</tr>
<tr>
<td>1. I tend to be more irritable with others since the death of my young patient.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2. I frequently experience angry feelings.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3. My arms and legs feel very heavy</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4. I have feelings of guilt because I was spared and the deceased was taken.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5. I feel lost and helpless.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>6. I have had frequent headaches since the death.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>7. I cry easily.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>8. Concentrating on things is difficult.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>9. I feel extremely anxious and unsettled.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>10. Sometimes I have a strong desire to scream.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>11. Life has lost its meaning for me.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>12. I am not feeling healthy.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>1</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------------------------------------------------------------</td>
<td>---</td>
</tr>
<tr>
<td>13.</td>
<td>I frequently feel depressed.</td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>I have the feeling that I am watching myself go through the motions of living.</td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Life seems empty and barren.</td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>I have frequent mood changes.</td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Small problems seem overwhelming.</td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>I have lost my appetite.</td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>I seem to have lost my energy.</td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>I seem to have lost my self-confidence.</td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>I usually feel unhappy.</td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>I am awake most of the night.</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX B -
PERMISSION TO MODIFY REVISED GRIEF EXPERIENCE INVENTORY

You have my permission to modify the RGEI in any way to meet the needs of your study. Some people have recoded the responses and others have not; it seems to be personal choice on the part of the researcher.

I wish you success with your study and I look forward to learning about the results.

Elise Lev

-------- Original Message -----------------
From: "William A. Sacks" <was455@js-net.com>
Date: Wed, 24 May 2000 09:08:06 -0700

>I have 2 questions regarding use of the RGEI:
>1) To make it more applicable when used with healthcare providers, I would like to rephrase #1 to read, "I tend to be more irritable with others since the death of my young patient." Is this rewording OK with you?
>
>2) You have arranged the Likert scale responses in a rather unusual fashion (agreement: slight-moderate-strong, disagreement: strong-moderate-slight) that then requires recoding of the responses. This seems very deliberate on your part. Please explain the reason for this. How does the order affect the responses, etc.
>
>I am very excited to see how this works with staff at a subacute peds facility. If all goes well, I will be collecting data this summer. Thank you for your help with this.
>
>Bill Sacks
>
>(909) 338-4067 - phone
>(909) 799-6205 - fax
APPENDIX C - DEMOGRAPHIC DATA

Personal:
Gender: ______ Female ______ Male

Age: ______ years

Marital status: ______ Single
    ______ Married
    ______ Separated
    ______ Divorced
    ______ Widowed

Ethnicity: ______ White
    ______ African-American
    ______ Hispanic
    ______ Filipino
    ______ Asian
    ______ Native American
    ______ Other

Please specify __________________________

Number of children: ______

Current living situation: ______ Live alone
    ______ With spouse
    ______ With family
    ______ With friend(s)

Did any of the following occur during the last year?
    ______ Death in the immediate family?
    ______ Diagnosis of major illness in the immediate family?
    ______ Divorce or other major loss?

Is there a person with whom you can talk to about your work? ______ yes ______ no
    If yes, is this person a friend, spouse, colleague, pastor? (circle all that apply)
        Is this help enough? ______ never ______ sometimes ______ mostly ______ always

Religious preference __________________________. Please indicate level of involvement with church activities/spiritual development:
    ______ not at all ______ somewhat ______ significant ______ very involved

Employment:
Position currently held: ______ CNA
    ______ LVN
    ______ RN
    ______ RT
    ______ Other, please specify __________________________

Length of employment at TKSH ______/______ (yrs/mos)

Length of employment in current position at TKSH ______/______ (yrs/mos)

______ AM shift ______ NOC shift

Number of years in healthcare ______

Number of patient deaths experienced this year ______

Education:
Year of Graduation/ Certificate received (complete all that apply):
    ______ High school ______ CNA cert.
    ______ A.A. ______ LVN license
    ______ BS/BA ______ RN license
    ______ MS/MA ______ RT license
    ______ Doctorate ______ Other, please specify
    ______ Other post-baccalaureate degree/certificate

Please specify certificate/year received:

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APPENDIX D - RESEARCH INTRODUCTION LETTER

Dear TK staff,

As most of you already know, I am a graduate student at Cal State University San Bernardino, working on my masters degree in Social Work. As part of my academic work and with the support of the TK administration, I am conducting a research project at Totally Kids on healthcare providers’ experience of grief. I would like to invite all CNAs, LVNs, RNs and RCPs to participate. Participation will require about 6-8 minutes of your time to complete 2 brief questionnaires. Your responses will be anonymous; you will not identify yourself on the returned questionnaires. Please be assured that your participation is totally voluntary; whether or not you participate will in no way affect your employment at Totally Kids. The information gained from this study will be used to help develop a Peer Support/Grief Management Program for staff at our facility. As an added incentive to participate, all those who return questionnaires will be entered in a lottery to be conducted when the data collection is completed (approximately 1 month). The winner of the lottery will receive $50.00. This will not require that you identify yourself on the questionnaires; my only requirement will be that the questionnaires are returned to me.

I will be contacting you in small groups and individually. At that time I will explain in more detail how this will work, and distribute forms to those of you who agree to participate.

I hope that you will join me in this project; the greater the number of participants, the more useful will the results be. We will all benefit from this effort.

Sincerely,
William Sacks
APPENDIX E - INFORMED CONSENT

The study in which you have agreed to participate is designed to evaluate the level of grief experienced by staff members at TKSH, compare these levels among the different caregiver disciplines, and evaluate relationships between personal/demographic factors and one’s experience of grief. It is being conducted by William Sacks, master's degree candidate in Social Work, under the supervision of Dr. Rosemary McCaslin, Professor of Social Work at CSUSB.

This study has been approved by the Institutional Review Board of California State University, San Bernardino and has the approval of the administration of this facility.

Your participation will involve completion of 2 questionnaires. All information that you provide will be anonymous. You will not identify yourself on any of the forms that you complete, and all results will be reported in group form. You will separate this signed consent from the 2 questionnaires before you return all completed forms to me – please leave the questionnaires stapled together.

Please understand that your participation in this research is strictly voluntary, and you are free to withdraw at any time without penalty. At the conclusion of this study (June 2001), you may receive a report of the results by contacting William Sacks.

If you have any questions or concerns regarding this study, you may contact Dr. Rosemary McCaslin at (909)880-5507.

With my mark, I acknowledge that I have been informed of and understand the nature and purpose of this study, and I freely consent to participate.

Please mark with “X” Date

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APPENDIX F - DEBRIEFING STATEMENT

Thank you for participating in this study –

The research that you have just participated in is designed to investigate the levels of grief experienced by healthcare providers and explore the relationships between personal factors (gender, age, education, etc.) and one’s personal level of grief experienced. It is being conducted by William Sacks, candidate for master’s degree in Social Work, under the supervision of Dr. Rosemary McCaslin, Professor of Social Work at CSUSB. This study has been approved by the Institutional Review Board of California State University, San Bernardino and has the approval of the administration of this facility.

All information is provided anonymously; there is no attempt to identify participants and their responses. All results will be reported by group (CNA, LVN, RN, and RCP). If you would like a copy of the results of this study, please contact William Sacks after June 2001.

If you have questions or concerns about this research, you may contact Dr. McCaslin at (909) 880-5507, California State University, San Bernardino.

If the questionnaires should raise personal issues for you which you feel need more assistance to address, please contact the Social Service staff at TKSH for assistance and/or additional referral information.

Thank you again,

William Sacks
To whom it may concern:

I have thoroughly reviewed the research proposal for a study on compound grief as experienced by healthcare providers, submitted by William Sacks. This review included examination of the study's purpose and procedures, data collection methods and questionnaires, as well as informed consent and debriefing statements. This study appears to be well conceived, and may provide valuable information for our facility's Staff Development and Social Service Departments while protecting staff anonymity and confidentiality. Mr. Sacks has my consent to conduct this study at Totally Kids Specialty Healthcare, pending approval by CSUSB Institutional Review Board.

I understand that this study is being conducted as partial fulfillment of the requirements for a Masters Degree in Social Work at Cal State University, San Bernardino. Further, I have been assured that I may contact Dr. Rosemary McCaslin, Professor of Social Work at CSUSB and research advisor, if I have questions or concerns regarding this project.

I look forward to receiving the results of this study when it is completed in June 2000.

Sincerely,

Gregg Beckham, Director of Ancillary Services
Totally Kids Specialty Healthcare
REFERENCES


