HOSPICE RESPITE CARE: VIEWS OF SOCIAL WORKERS

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HOSPICE RESPITE CARE: VIEWS OF SOCIAL WORKERS

A Project

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Division of Social Work
Abstract

of

HOSPICE CARE: VIEWS OF SOCIAL WORKERS

by

Randy R. Neblett

The professional literature shows that the majority of people at the end of life prefer to die at home. Family caregivers are essential for this to be possible, but there is little evidence available as to what types of assistance they need to be effective in this role. There is a gap in the literature regarding the impact of respite care on caregivers and this study attempts to fill that gap with a survey of social workers’ views on respite care. The participants in this study include 18 social workers, employed by four different hospice agencies within the Sacramento Hospice Consortium. Participants completed a 10-question survey eliciting information regarding their viewpoints on the respite care programs offered by their agencies. Findings provide information that the most significant factor influencing social workers assessment of the efficacy of their respite programs was how often the perceived need for respite care was met. The most often utilized respite program was a 5-day respite benefit in a skilled nursing facility, despite the problems associated with them of frequently undesirable geographic location, bed unavailability and in particular patient preference. Creating new locations in which to receive this 5-day benefit such as the patients’ home or residential care facility were ways
of improving patient satisfaction with a more homelike setting. The idea of a home-style inpatient hospice facility for respite care was unanimously approved by all the social workers, although feasibility due to cost was a concern.

_____________________________, Committee Chair
Joyce Burris, PhD, MSW.

____________________________
Date
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To the many people who contributed to my efforts in writing this project, I would like to thank them at this time. First, my thanks to my late mother who was the inspiration for this work as her desire to die at home was honored by our family and we were so ably assisted by the hospice team to be successful in granting her last wish. To my husband for his enthusiasm and loving support, without which none of this work could have been completed. To my professors and especially my thesis advisor, Joyce Burris, PhD, MSW for all their wisdom and patient instruction, many thanks. And lastly, my thanks goes to all the hospice patients and their families who have taught me the importance of living life each day to it’s fullest and to be grateful for every moment we have together.
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Chapter 1
THE PROBLEM

Introduction

It is the inability of informal caregivers to continue giving care at home that is one of the most common reasons for unplanned admission to facilities at the end of life. Despite the fact that most people prefer to die at home, the majority are unable to do so. This researchers’ interest in this problem is a direct result of a personal experience of participating in creating an environment where a family member’s last wish to die at home was made possible. To deny anyone the dignity of choice regarding their place of death because of lack of support with respite care is incongruent with the social work mission of enhancing human well-being and advocating for the needs of those most vulnerable who are unable to do so for themselves. It seems both morally and professionally imperative that more attention be given to identifying what types of respite services patients and their families need to support them in fulfilling their desire to die at home. This researcher intends to explore the needs for hospice respite care in the community served by the Sacramento Hospice Consortium, to examine the scope of the services offered and to assess how well the needs are being served.

Background of the Problem

It is recognized in the literature that there is a gap in this particular area of knowledge regarding the impact of respite on caregivers (Ingleton, 2003). The overwhelming preponderance of research has been conducted abroad, primarily in the United Kingdom. This researcher believes such data is applicable to this study despite the
differences of healthcare delivery systems; as the majority of hospice care in the United States is funded through the federal program of Medicare. It is this researcher’s belief that exploring this field and collecting some basic information will contribute to the larger social work domain by providing data that has the potential to improve the delivery of respite care services within this community.

There is a valid concern that is identified in the literature that caregivers need for respite care services are not being adequately met, leading to the failure of hospice programs in meeting the terminally ill patients’ desire to die at home. So, with all the information about the importance and desired need for hospice care services that would allow people the dignity of choice regarding their pace of death, why are most still denied this human right? According to researcher Sheila Payne (2004): “One of the major reasons for admission of patients to hospital in the late stage disease is the inability of carers to continue to provide care at home” (p. 692). Harding (2003) agrees; “The carer can be seen as holding a unique position of both providing and needing support, and it has been suggested that it is sometimes unclear who is ‘the patient’” (p. 63). This is an area of research that has not been investigated until recently. According to Ingleton (2003); “Relatively little attention has been directed towards identifying the needs of caregivers who find themselves in this position and what interventions (if any) might best support them in continuing to provide care to the patient during the illness and the dying trajectory” (p. 567). It can be seen that this is an area needing further study and more data to help contribute to the existing professional knowledge base. This researcher hopes to
add to the existing database by contributing findings about what services are currently available to individuals and their families for respite care in this community and how well those services meet the bio-psycho-social-spiritual needs for well-being of both caregivers and patients. In addition, information regarding ideas for improving respite programs will be gathered as well.

There are some larger cultural factors that influence this research problem that need to be considered. One of the most significant is the problem of how our society views death and the process of dying as a topic best avoided. Elizabeth Clark, PhD, ACSW, MPH and Director of the NASW (2009) recently wrote in an article, ‘Death Panel’ Rhetoric Sets Us Back, that death had replaced sex as the most taboo topic for our society. The term the “pornography of death” was coined in 1995 by a British social anthropologist, Geoffrey Gorer, to describe a concept he felt represented the social mores of Americans regarding death. This term can be loosely defined as death separated from its natural emotion of grief. Clark (2009) proposes that this concept is as relevant today as it was then. She says that we are a death-avoiding society:

…but only when we are talking about the actual physical death of a loved one. Out of touch with death as a natural phenomenon, we have become fascinated with death in many other forms. Every day we are surrounded by death imagery, and we use death to sell things such as newspapers, movies and video games (p. 1)

She goes on to remark how death was recently used to sell a political viewpoint in the healthcare reform movement, the so-called “death panel” scare tactic. Just talking about death in a direct way stirred the nation’s deepest fears and suddenly the private
sector and political figures alike were terrified by the thought that not only was death universal, we might have no control over it. As Clark (2009) said, “Fear always trumps logic…” (p. 1). The chance to begin to have open discussions about death and advanced directives to help ensure that individuals be assisted in making their own choices regarding end of life decisions was ended before it even began.

This pervasive attitude of refusing to see death as a natural process and hiding from the ultimate reality of facing their own eventual demise helps to create a situation where other fears of the deepest kind are waiting just below the surface to arise. Virginia Satir (1998) renowned pioneer of family therapy, noted in her book, The New Peoplemaking, that while death is a difficult subject to talk about frankly and openly; “living is meaningless unless we see dying as a natural, inevitable and essential part of life” (p. 262). She goes on to say how secrecy around death contributes to fear and the inability to process the loss can create situations in the future where other fearful reactions become tied to it. “Death is death. It happens only once in a lifetime. No other thing in life is like it. When you make this distinction, then everything except the act of death is life. To treat it in any other way is a travesty on life” (p. 265).

This element of how unresolved issues regarding death can become significant problems is addressed by J. William Worden (2002) in his book, Grief Counseling and Grief Therapy. He mentions the work of Aaron Lazar who believes from his research that 10-15% of the clients in his mental health clinic at Massachusetts General Hospital have underlying unresolved grief reactions that impact negatively in clients lives (Worden, 2002). Assisting family members prior to death to meet their own basic bio-
psycho-emotional needs by providing respite services could make a difference later on in the grieving process for a more positive outcome.

Another important influence impacting respite care concerns the radically different way that the nature of illness has changed in the past 100 years. Hallenbeck (2003) notes that in 1900, most people died from illnesses that were relatively sudden in onset and resulted in death within a few days, requiring little family support or need for respite care. Today, however, the picture is quite different as the most common causes of death are due to prolonged, chronic illnesses requiring lengthy periods of caregiving and increased needs for family support systems. These huge changes affect all of us and we are being challenged to rethink the way we respond to the new demands that the modern forms of illness and dying bring.

These factors may be a part of the reason why country’s largest healthcare system, Medicare, refuses to address the concerns of inadequate respite care programs. But perhaps the largest factor in solving the problem of adequate respite care provisions is the financial aspect. Medicare reimburses about $5.00 more per day for inpatient respite care; $144.79 for home respite vs. $139.97 for inpatient (Medicare Benefit Policy Manual, 2009). When the additional costs required to offer inpatient respite are considered, it is obvious that $5.00 per day wouldn’t cover those costs. In the greater Sacramento metropolitan area, the only options for inpatient hospice respite care are either a skilled nursing facility or an acute-care hospital, which is limited to no more than 5 days at a time. For most patients and their families these choices are not acceptable as they are far from the homelike atmosphere desired and many do not utilize this option. Utilization of
inpatient respite care is usually left as a last resort when pain or other symptoms become so unmanageable that the patient can no longer remain at home. Nationwide, in 2007 only 0.2% of Medicare patients utilized respite care, the other levels of care were: Routine Home Care 95.6%, General Inpatient Care 3.3% and Continuous Care 0.9% (NHPCO, 2008). These figures reflect what this researcher believes is a significant failure of our healthcare system to provide for the respite care needs of the dying. This can be particularly seen in comparison to programs in England and Australia; both countries offer diverse forms of both inpatient and home-based respite care programs, including day care centers, in-home night respite and short term institutional care lasting from 2-6 weeks (Skilbeck, 2005). The only home-based respite care in this country comes from volunteers, at a maximum rate of 4 hours a week; any other home-based services required must be paid for by the patient out of pocket.

The scope and magnitude of this problem is huge and will affect everyone eventually, either directly or through a friend or family member’s experience. Identifying the problem and the factors that influence its’ solution is the first step of the process towards resolution. This first step must begin with a shift in the cultural perspective of death. Dr. Elisabeth Kubler-Ross (1975) probably said it best in her book, Death: The Final Stage of Growth:

Death can be very hard to face, and we might be tempted to avoid it and flee from having to confront it. But if you have the courage to deal with it when it comes into your life-to accept it as an important and valuable part of life-then, whether
you are facing your own death, that of someone in your care, or that of a loved one, you will grow (p. 117)

Statement of the Research Problem

The research problem is that there is a lack of knowledge regarding the effectiveness of the respite care programs offered by the hospice agencies comprising the Sacramento Hospice Consortium. Lack of such information makes it difficult, if not impossible; to determine whether the bio-psycho-social-spiritual needs of hospice patients and their families are being met or not.

Purpose of the Study

The primary purpose of this study is to gather information collected from a survey assessing the respite care programs of each of the seven hospice facilities in the Sacramento Hospice Consortium (SHC) and to evaluate their effectiveness. The secondary purpose of this study might be to use the results of this study to show how respite care programs could be improved to better meet the needs of the hospice patients and families in this community.

Personal Interest in the Problem

This researcher’s interest in this topic originated from the personal experience of collaborating with Sutter VNA and Hospice during the end of life of my mother five years ago. It was during this stressful time that it became very clear how difficult it was to provide around the clock care for another person. Despite the fact that my prior career as home health nurse RN had well prepared me for the task, the presence of my physician husband and two sisters at the bedside for assistance; it was all we could manage to do
for a relatively short period before her death at home transpired. What on earth do other people do who have fewer resources than we did? The answer is, they struggle and have severe needs for respite care programs that simply don’t exist. If financial resources are plentiful, private caregivers can be hired, but for those without such means, most hospice respite care is limited to volunteers who come once a week for four hours. Medicare does provide limited 5 day stays for caregiver respite, but these are primarily at skilled nursing facilities, and most patients and their loved ones do not feel that this is a viable option for quality end of life care. The experience we had as a family that enabled my mother to die where she wanted, in our home, was a very special and rewarding one. She died in peace and with love, surrounded by her loving pets and family. It’s the way that most would agree is how we would wish to die, but it requires huge support to achieve. This is why this researcher became interested in this topic; to assist others in the process of dying to be able to die in dignity and in the place of their choosing. It is a gift that must be made available to everyone who wishes it.

Theoretical Framework

The broad application of humanism provides the foundation for those theories included in this discussion of the theoretical framework in this research project. Social constructivism is an important theory in helping to bring understanding to some of the different factors that contribute to the research problem. According to this theory, meaning emerges from a complex interweaving of relationships, interactions and social processes. As individuals interrelate and talk to others, meaning is generated and agreed upon. Social realities are constantly being reconstructed and are never static. Our current
mainstream cultural and societal construction of the meaning of the end of life experience is to deny the fact for as long as possible and to avoid talking about it. This denial of death contributes to the lack of planning for adequate respite care programs. As the hospice movement continues to expand and educate more people, eventually these ideas about death will be deconstructed and reconstructed in ways that include death as a part of life.

Dr. Elisabeth Kubler-Ross (1969) in her landmark book, On Death and Dying, theorized that this dynamic of denial contributes greatly to unnecessary suffering for the dying. Her belief is that modern medical advancements have contributed to a climate where the dying are overlooked as human beings and are treated as objects where cure becomes the total focus. She challenges the medical profession when she asks:

Is this approach our own way to cope with and repress the anxieties that a terminally ill patient evokes in us? Is our concentration on equipment, on blood pressure our desperate attempt to deny the impending death which is so frightening…that we displace all our knowledge onto machines, since they are less close to us than the suffering face of another human being which would remind us once more of our lack of omnipotence, our own limits and failures, and last but not least perhaps our own mortality (p. 9)

Nearly 40 years later, these thoughts are still applicable in many situations and are part of the reason why the need for respite care programs is neither anticipated nor planned.

model about the process that occurs when a loss is experienced. According to his model; the first “task” is to accept the reality of the loss, to overcome the initial shock and denial that is present. This can also apply to the anticipatory grief experienced by patients and their families upon hearing the terminal diagnosis as they face the loss of life as they knew it. Sometimes this denial reaction can be intact for a significant length of time, up to and including the time of death; which creates a situation where the creation of a palliative care program is difficult if not impossible.

The micro theory that is most applicable to this research topic is one founded in the humanistic ideals of self-determination, self-fulfillment and self-actualization. Although the strengths-based engagement (SBE) approach is more accurately described as an overarching philosophical posture (Bertolino, 2010); it’s usefulness in helping to understand the dynamics of this research problem is undeniable. The core principles of SBE include processes that are client-centered and include assessments of internal strengths and external resources (Bertolino, 2010). The narrative expressed by the client is listened to and given highest regard in creating the plan of care. When the clients’ choice for location of death is honored and supported by programs that enable family support systems to provide for homecare needs, then the opportunity for self-actualization is created.

Research Question

The research question is: How well are the hospice respite care needs of the community being met by the agencies that comprise the Sacramento Hospice Consortium?
Assumptions

One of the assumptions inherent in this study is that the workers who provide services have equal knowledge, education, and training at all the agencies within the Sacramento Hospice Consortium as each agency must meet requirements for certification and accreditation. It is an assumption that all the survey respondents will answer the questions honestly, to help ensure this the anonymity of the survey respondents will be kept confidential. Another assumption is that all the agencies do, in fact, have respite care programs. Finally, the assumption is made that respite care programs are experienced as helpful and beneficial for the hospice community.

Justification

This research project will contribute to the preliminary data base regarding respite care programs in the local community, as no such information currently exists. This information may serve as a foundation for further inquiry into this topic which has been identified worldwide as needing more investigation. Further research studies could be conducted building upon the data base retrieved from this study, in particular expanding data collection to include the recipients of respite care, the dying and their families. The primary mission of the social work profession is to enhance human wellbeing and meet the basic human needs of all people, especially the vulnerable. The dying and their families deserve to have the dignity and worth of being included in their plans for end of life care and supported in any way that is needed. This study can be seen as a small beginning, a first step, on a journey that will hopefully someday enable everyone to have their choices and decisions about end of life heard.
Delimitations

This study is limited to the seven hospice agencies comprising the Sacramento Hospice Consortium. Any other hospice agencies in the Sacramento and Placer regions are not a part of this study and no claims about their respite care programs can be made.

Summary

This chapter has introduced the problem of how difficult it is to discuss death and dying. It remains a topic that is considered taboo by many and creates more anxiety and fear than any other experience in life. This death denying attitude has contributed to the current lack of information and research regarding end of life choices and the programs designed to support individuals and their families. The importance of respite care programs and the factors impeding their further development was discussed. Finally, the relationship between this topic and professional social work ethics and values was illustrated as extremely significant, giving this study a status worthy of investigation. In the next chapter, the historical perspective of hospice care will show the evolution of modern day hospice care and how many different approaches are utilized in other countries. Further, detailed explanations will be given of the significance of respite care programs and how they impact on the success of hospice programs and their ability to meet the bio-psycho-social- spiritual needs of patients and families. Finally, by bringing death out of the closet and facing the fear of the unknown it may be possible to create acceptance of our own finiteness and ultimately to live our lives with renewed meaning.
Chapter 2

THE LITERATURE REVIEW

Introduction

This review of the current, professional literature will begin with the presentation of a historical perspective of the hospice movement, tracing it’s beginning from medieval times to the present day. A timeline focused on the development of hospice and palliative care in the United States will follow. Definitions of hospice and palliative care will help to clarify understanding of these concepts as terminology continues to evolve in this field. Next, a discussion of the philosophy that emerged as two pioneers in the field began their work as leaders of this movement and how it continues today. The implications for practice regarding hospice care will be discussed relevant to the NASW Code of Ethics in addition to how demographic changes are influencing the magnitude of this issue. The importance and relevance of respite care in hospice programs will be demonstrated as fundamental to achieving successful outcomes for the dying and their families. This will be followed by a presentation and discussion of the various types of respite care programs. Finally, the review will conclude with the consideration of how important it is to find meaning and peace in the face of terminal illness and death. Indeed of how essential it is to everyone involved in the experience; whether they are the dying individual, their loved ones or members of the multi-disciplinary team of professional caregivers.
History of the Hospice Movement

Societies from antiquity have all shared some traditions for caring for the sick and dying. Most sources agree that the word “hospice” was first used in the fourth century to describe places of refuge where Christian orders offered shelter to weary pilgrims, the sick and the destitute. The word hospice comes from the Latin *hospitium*, meaning hospitality, and from the old French word *hospes*, or host (Hallenbeck, 2003). The first institution built specifically to offer care to the dying, the Dames de Calaire, was founded in France by Mme Jeanne Garnier in 1842 (Saunders, 2000). In 1879, the Irish Sisters of Charity opened Our Lady’s Hospice in Dublin, followed by St. Joseph’s Hospice in London in 1905. It was Dame Cicely Saunders work at St. Joseph’s and St. Luke’s Hospital (Home for the Dying Poor founded in England in 1893) that led to the founding of the first modern hospice, St. Christopher’s Hospice in 1967 (Saunders, 2000). It was during this time that she introduced the idea of hospice care to the United States, on a visit in 1963 to Yale University. Her lecture regarding the concepts of holistic hospice care given to medical students, nurses, social workers and chaplains launched a chain of events that led to the development of the modern hospice movement of today (Clark, 2007; Conner, 2007).

Timeline of the Development of Hospice and Palliative Care in the United States

1965: Dr. Saunders invited to become a visiting faculty member at the Yale School of Nursing.
1969: Dr. Elisabeth Kubler-Ross writes a book based on more than 500 interviews with dying patients, entitled, *On Death and Dying*, that changes the way many view death.


1978: The National Hospice Organization is formed.

1979: The Health Care Financing Administration (HCFA) initiates demonstration programs at 26 hospices nationwide to evaluate hospice costs and services.

1982: Hospice Medicare Benefit (MHB) created via an amendment to the Social Security Act with a 1985 sunset provision.

1984: Joint Commission on Accreditation of Hospitals (JCAHO) begins hospice accreditation.

1985: MHB made permanent by Congress with option for states to include it in their Medicaid programs.

1990-1999: The growing end-of-life movement brings increasing national interest in quality of life at the end of life as well as increasing public awareness and physician education.

1999: National Hospice organization (NHO) changes its name to the National Hospice and Palliative Care Organization (NHPCO) reflecting the extension of hospice care to include palliative care in the U.S.

2000-2006: Number of hospice sites grows to more than 4,000 and the NHPCO reports that 64% of them also provide palliative care outside of their hospice programs.

Present: The American Board of Medical Specialties recognizes hospice and
palliative medicine as sub-specialties. The Hospice and Palliative Nurses Association offers certification for advanced practice nurses. A National Palliative Care research Center has been initiated by the Center to Advance Palliative Care (Conner, 2007; NHPCO, 2008).

Definitions of Terminology

What is hospice? The meaning of the word hospice has different interpretations for many and can be confusing as well. It can mean a place or facility where people go to receive end of life care or a program of humane, holistic and supportive care for the terminally ill and their families (DuBois, 1980; NHO, 1993). Or it can be both of these at the same time. The original idea of hospice was as a place or specific facility where terminal care was given to the dying in a person centered way. In the United Kingdom, inpatient hospice facilities were the most common site for end of life services, but changing patterns of care for terminally ill people now means that 90% of people spend the majority of their last year of life at home (Skilbeck, et al, 2005). In the U.S., most people consider hospice to be a special concept of care that provides comfort and support to patients and their families when life threatening illness no longer can be cured. Hospice is seen as an alternative to hospitalization that has its focus on maintaining the patient’s home as the primary location for treatment that includes symptom relief from pain and discomfort. It is a holistic approach, which includes a multidisciplinary team of professionals that deals with the emotional, social and spiritual aspects of the effects of terminal illness on patients and their families. A variety of counseling and bereavement
services are available before and after death (Conner, 1998; DuBois, 1980; National Hospice and Palliative Care Organization, 2003).

Palliative care may be a term unfamiliar to many. But for most of history until the past 100 years or so, much of medical treatment was probably palliative in purpose and effect because there was so little actual curative treatment available. The dictionary defines *palliate* as ‘to alleviate without curing’ (Beresford, 2007). Palliative care is sometimes used interchangeably with hospice care and indeed both have much in common. The root word from the Latin, *palliare*, means to cloak or shield or to protect (Hallenbeck, 2003). The modern use of the term is attributed to Dr. Balfour Mount, one of the founders of the North American hospice/palliative care movement working in Montreal (Hallenbeck, 2003). The World Health Organization first formally defined palliative care in 1989. The most recent definition from that source, published in 2002, states: “palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (Clark, 2007, p. 437). Palliative care seeks to alleviate the suffering associated with all illness, not only terminal diagnoses. The American Academy of Hospice and Palliative Medicine defines it as originally referring to the care of patients with terminal illness, but now refers to the care of patients with life-limiting illness, whether or not they are imminently dying (Hallenbeck, 2003). In recent years, many organizations have changed their names to reflect this increased scope. The principles of palliative care are
applicable at any stage in the course of a patient’s illness (Forbes, 2003). According to Forbes (2003) the evolution and current usage of the terms can perhaps be best understood by the following in the figure below.

\[ \text{Figure 1. In Reality the Stages are a Continuum} \]

**Philosophy of Hospice and Palliative Care**

Dame Cicely Saunders is acknowledged by many to be the founder of the modern hospice movement. Nurse, social worker and medical doctor, she challenged the status quo of the Western world’s view of care for the terminally ill. In 1948 she was a novice social worker at a hospital in London where she was inspired by a terminally ill patient, David Tasma, a 40-year old hospitalized with inoperable cancer (Saunders, 2000). She learned from him that dying people were not receiving the medical care they needed, the dignity of holistic treatment for the dying process. During conversations with him, the two discussed how she might someday open a facility better suited to providing not only the treatment of pain control, but treatment of emotional, spiritual and social pain as well. When he died, his legacy of 500 pounds (equal to about $500 US) was left to her to begin the work they had discussed. He told Saunders, “I will be the window in your Home” (Saunders, 2000, p. 8). She eventually returned to medical school to receive her medical
degree, determined to make a difference in the way the dying were being treated. In 1959, newly qualified in medicine and working as a research fellow at St. Joseph’s Hospice in London, UK, she published *The Management of Patients in the Terminal Stage*, the only important article of its kind in a six-volume series on cancer (Saunders, 1960). She was instrumental in creating a new paradigm for the healthcare of the dying. Part of her philosophy was the concept of ‘total pain’. Her writings about her case study experiences with over 1100 terminally ill patients brought forth the relationship between physical and emotional suffering, that each was capable of affecting the other. It was her belief that physical symptom control comes first, but it could not be treated effectively without also giving attention to the psychological, social and spiritual needs of patients and their families. This type of approach requires the resources of a multidisciplinary team of health professionals; doctors, nurses, social workers, chaplains; enhanced by the services of trained volunteers. These teams can operate in the hospice facility, hospitals or at home (Saunders, 2000).

It took 19 years after that encounter with David Tasma to build St. Christopher’s Hospice in 1967 (Clark, 2007). It stands as a model of hospice care where people are “helped not only to die peacefully, but to live until they die with their needs and their potential met as fully as possible” (Saunders, 2000, p. 8). In the years since, it has inspired people in many countries worldwide to begin their own interpretation of palliative care, showing that the basic principles can be interpreted in diverse cultures with positive results (Clark, 2007).
Dr. Elisabeth Kubler-Ross, a native of Switzerland and an American psychiatrist became a pioneer in the field of thanatology, the study of death and dying. She published her first book, *On Death and Dying*, which became a best-seller (Kubler-Ross, 1969). It was a result of her work over two and a half years based on over 500 interviews with dying patients that she presented during weekly seminars to students at the University of Chicago. Her focus was to re-humanize the population of dying individuals to the medical profession, to confront the fear and secrecy of death in our culture and to acknowledge how important it is to learn from the dying about their experiences. She argued that home-care was preferable to in-patient hospital care and that patients should have a voice and a choice in the place of death. She made a significant impact on the professional medical community, who became more aware and responsive to the needs of the dying and their families.

In her later work, *Death: The Final Stage of Growth* (1975), she explores some interesting aspects regarding her own philosophy that developed from years of contact with the dying. She answers the question of how death and growth can be partners in bringing new meaning and freedom to life. She suggests that as members of society, we can become so captive to the cultural and social stereotypes that define what others expect of us, that we lose the ability to become self-actualized into the authentic unique person we were meant to become. It is only when faced with the imminent finality of death that many finally find the courage and strength to reject those outside roles and begin to devote each moment of every day to becoming truly authentic. She says we should not fear death of the physical body, but our concern should be to really live while
we are alive; “…to release our inner selves from the spiritual death that comes with living behind a façade designed to conform to external definitions of who and what we are” (Kubler-Ross, 1975, p. 164).

Her own perspective about death is that many members in our modern society have lost the understanding that death is a natural and integral part of life. We have made discussing it taboo; shield our children from it in an effort to protect them; and continue to rely on advanced medical interventions to keep our denial intact. Most people still die in a hospital setting, where there is an emphasis on curing disease and saving lives, not assisting with the needs of someone who is no longer able to be saved. Most physicians are trained to save lives and have little or no training to deal with death and dying. These patients represent a failure of the medical world and many physicians have difficulty in recognizing when caring for the patient means letting go of treating the disease process (Kubler-Ross, 1975).

Dr. James Hallenbeck in his book, Palliative Care Perspectives (2003), brings up an interesting explanation for understanding this attitude among health practitioners that is still common today, nearly 35 years later. Scientific advances in cardiopulmonary resuscitation (CPR) during the early 1960’s and treatment successes in using antibiotics for formerly fatal illnesses created a shift in the way illness and the role of medicine were perceived. He calls it the “cult of cure” (p. 4), where the goal of medicine moved from healing to cure. People began to believe that everything could be cured. The human body was viewed as a machine with working parts that when needed could be “fixed”. But of course, no one could stay “fixed” forever; and when death ultimately presented itself, the
power of the belief in the cult of cure was so strong that it denied the existence of the
dying as people. When Kubler-Ross began her research, she was told that there weren’t
any dying patients in the hospital (Kubler-Ross, 1969).

There is no doubt though that attitudes towards death and dying have changed
over the years as the hospice movement began to create new constructs for
understanding. In more recent history, the 1990’s, there have been some great
advancements in the training of physicians. In 1993, the first major textbook, The Oxford
Textbook of Palliative Care Medicine was published. In California, a new law requires all
physicians to receive 12 continuing education hours in pain and end of life care between
2002 and 2006 in order to be relicensed. The American Academy of Medical Colleges to
the American Board of Internal Medicine, now both require some training in palliative
care. These changes are reflective of how changed attitudes are beginning to educate
providers to care for the terminally ill (Hallenbeck, 2003).

However, much of the philosophy that the early pioneers of this movement
Want, wrote about his experiences over a 10 year period working with the terminally ill.
Like Kubler-Ross, he advises that it is the dying themselves who are our best teachers.
His methodology was one he termed “existential phenomenology,” or a way of really
listening, to bear witness to the experience of living while dying with a terminal illness.
He found, as Cicely Saunders did, that pain is always both physical and psychological.
Once physical pain is controlled, as it can be in the majority of cases, the emotional and
spiritual pain can be addressed. The necessity for multidisciplinary care is affirmed. His
primary message is that people who are dying are still living and that dying presents the opportunity for growth and can propel someone into the search for self-realization.

**Implications for Practice**

The implications for social work practice regarding hospice care are many. Advocating for basic human rights is a commitment of the profession and according to the charter of the United Nations and the Universal Declaration of Human Rights, Article 25:

> Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. (¶ 1)

According to the National Association of Social Workers Code of Ethics (1999) the primary mission of the social work profession is “to enhance human well-being and help meet the basic human needs of all people, with a particular attention to the needs and empowerment of people who are vulnerable…”(NASW, 1999). The concern of social work for the basic human rights of individuals surely must include the right to die well in the way that one chooses.

The implications for practice of this topic are significant when viewed in light of the current demographics of the 21st century. In their article, *Living Well at the End of Life* (2003) the authors, Adamson and Lynn, cite how drastically the way people live and die in the past century has changed. In the 1900’s average life expectancy was 47 years
and death was usually the cause of an acute or sudden illness; taking days or weeks to occur with family caregivers at home. In 2000, the average life expectancy was 75 years; likely cause of death was due to heart disease, cancer, stroke, injury, and diabetes. Americans live longer, healthier lives than ever before, but with this benefit come challenges. Our current health care system will need to change in order to accommodate for the changing health care needs of the aged who have multiple chronic disabilities and illnesses that require palliative care services. The profession of social work is in a perfect position from which to advocate for such changes that enhance the well-being of this vulnerable population (Adamson, 2003).

Current Demographics

Added to this is the rising population of older adults, the “Baby Boomers”, whose numbers by 2030 many experts project will be from a conservative estimate of 35 to a possible 70 million people, one-fifth of the U.S. population will be over the age of 65. Of these, nearly 9 million will be 85 or older and facing the prospect of significant disability. This population explosion will drive an elder boom and the need for healthcare services, including palliative and hospice care, will be a dominant challenge in the next 20 years. If these projections prove correct, then more than twice as many hospice facilities and services will be needed to meet the growing need for palliative care of this expected elder boom (Adamson, 2003; Connor, 2007; Hallenbeck, 2003).

Another significant factor to consider is that a range of studies of people suffering from a progressive illness show that most, from 50% up to 75%, would prefer to die at home (Department of Health, 2008). The World Health Organization confirms that most
studies are estimating 75% of respondents prefer to die at home, although as death becomes imminent, part of this group may come to prefer inpatient care (Higginson, 2004; NCPC, 2007). These figures are in direct contrast to the reality of the actual location of death experienced by most. Only 42% of dying people are actually able to do so in their private residence, with another 27% dying in their place of residence in either a nursing or residential care facility (NHPCO, 2008). According to the same source, in 2007 about 1.4 million people received new or continuing hospice care, twice as many as a decade ago. The proportion of U.S. deaths served by a hospice program is estimated at 38.8% for 2007 (NHPCO, 2008; Hannon, 2008).

The number of hospice providers has grown in the recent past as demands for care have increased, 2007 estimates by the NHPCO are that 4,700 hospice facilities are currently in operation. This growth has been fueled both by the increased cultural and professional acceptance of hospice as part of the health-care system and by the Medicare program of reimbursement for hospice services (MHB), permanently implemented in 1985 (Connors, 2007).

Changes in Diagnosis of Hospice Populations

But with this growth have come significant changes in patient population and length of stay that have challenged and comprised nearly all hospice provider systems. The hospice movement has historically been utilized by people suffering from terminal cancer diagnoses. As recently as 1992, cancer patients comprised 75% of hospice patients. Ten years later, in 2002; cancer diagnoses had declined to only 43% (Nicosia, 2006). Other studies support these figures, citing a change in the past 25 years from
almost 90% cancer diagnoses to less than 50% in 2005 (Conner, 2007). The NHPCO figures for 2007 lists the primary diagnosis of all malignancies at 41.3% and non-cancer diagnoses (including heart disease, unspecified debility, dementia, lung disease, stroke, kidney disease, motor neuron, liver and HIV/AIDS) at 58%. When the focus was on treatment for terminal cancer, the support needed was typically shorter in length, allowing valued but limited resources to be spread out. Because of the shift from primarily cancer diagnoses to non-cancer illnesses, much more palliative care support is needed over a much longer period of time. Patients with non-cancer diagnoses, such as congestive heart failure, Alzheimer’s, or stroke, may differ significantly in the intensity of services used as well as the types of service used. As noted earlier, the continuum of hospice and palliative care needs are in a constant state of flux with people coming in and out of hospices and facing much longer periods of both sickness and health; straining the resources available to them (Beresford, 2007; Nicosia, 2006).

**Changes in Diversity and Geographic Areas**

Other, broader demographic changes also have impacted on the utilization of hospice and palliative care services. Patient ethnicity and race have played a significant factor is whether hospice is used or not. In 2007, the NHPCO reports that Caucasians account for 81.3% of usage, Latinos 5.1%, Black/African American 9.0%, multiracial or other 7.8% and Native American/Alaskan 0.3%. There is also great disparity of usage in different geographic regions, ranging from a high of 49% of all deaths in Arizona to a low of 11% in Alaska in a report from 2002. Rural areas have less access in general as well (Conner, 2007). These are areas of concern where social work professionals are of
unique and needed assistance to help in bringing more equality to service availability and usage.

*Changes in Length of Service*

Another factor impacting the hospice and palliative care field is the change in length of service. In 2005, average length of service dropped from 70 days to less than 50 days, perhaps more significant, the median time in hospice dropped to about 20 days. Sources agree that there is considerable and substantial variation in the intensity of care during a stay, with higher levels incurring greater cost at the beginning and end of the stay. With shorter lengths of stay becoming more common, it is difficult for providers to recoup these costs which would otherwise be spread out among the intervening days of treatment. Hospices have a greater proportion of higher-cost days as payment is a constant per diem rate; this has created budget shortfalls of 5-12 percent according to a recent study. Policy changes clearly need to be made to address the current system of Medicare reimbursement; adjusting per diem amounts to reflect the higher resource usage at the beginning and ends of stays would be a good start (Connor, 2007; Huskamp, 2001; Nicosia, 2006).

It is clear from looking at all the information regarding recent and future demographic changes that the social work profession has its place in the ever growing field of hospice and palliative care. From the need for social policy change at the macro level of intervention to the need for a greater number of more highly skilled specialists in palliative care, the opportunities to implement social change is great. This researcher advocates for a new system of certified social work palliative care specialists to emerge
like the United Kingdom has seen in recent years. Specialist palliative care certification is currently available to physicians and nurses who work in this field, it is certainly time to include the social work profession as well (Beresford, 2007).

Respite Care: Importance and Relevance in Hospice

From an extensive review of the professional literature, it is clear that many studies, from Australia, Europe and the U.S., have been generated to explore various aspects regarding hospice and palliative care. Several sources conclude that there is consistent and well researched evidence that palliative care services reduce the symptom burden and improves quality of life of both patients and family caregivers. The reduction of expenditures associated with hospitalization and cost-effectiveness of hospice programs have also been demonstrated by many sources. In addition, the personal wishes and desires of the terminally ill to die in their own home have been documented in studies here in the U.S. and more recently, in the United Kingdom (Hatzianandreu, 2008; NCPC, 2007; Nicosia, 2006). What is lacking currently in all geographic areas is rigorously researched evidence based information focused on understanding the family caregivers’ needs for information and respite care. Relatively little attention has been given to this topic of identifying the needs of caregivers and what type of support is best to meet those needs. There is a gap in the knowledge base of how respite care impacts the informal caregiver. Perhaps, in part this has been due to the fact that in Europe, historically most hospice care has been delivered in facilities, not in the home setting. This is changing now as more people in the U.K. (64-74%) surveyed prefer to die at home (Docherty, 2008; Grande, 2009; Harding, 2003; Ingleton, 2003).
There is some evidence however, of certain characteristics of family carers that need to be considered in creating effective respite programs for home-based palliative care. It is essential to recognize that individuals are unique and while they may share certain experiences, their needs may vary significantly. One important example is to recognize that individual needs will vary with differing relationships (i.e. spouse vs. adult child). Palliative caregivers also tend to give higher priority to the needs of the care recipient and to discount their own, setting themselves up for a situation that decreases their emotional and physical well-being. There is great ambivalence as well in accepting help from others when the caregiver feels like the expert and no one else knows how to care for the recipient as well as they do. Many caregivers find great personal satisfaction in providing care to a loved one and it is important to remember that the stress and satisfaction duality that exists in the relationship should be considered in the design of any support system. Caregivers need to feel supported in their role, but not replaced (Zapart, 2007). One approach is to adopt a more collaborative approach to service delivery where the professional is seen as a partner rather than the expert, and the expertise of the family carer is valued and acknowledged (Green, 2006).

Why is this topic of respite care services so important and relevant to hospice and palliative care? According to many researchers, one of the major reasons for admission of patients in the late stages of terminal illness is the inability of family members to continue to provide care at home. The caregiver has a unique position of both giving and needing support, and sometimes it may be unclear who the patient is. They are central to the achievement of end of life goals for death at home and while their participation is
frequently willing and motivated, it is essential that they be given the help they require in order to continue in their role without significant cost to their own physical or emotional well-being (Docherty, 2008; Grande, 2009; Payne, 2004).

It is important to define what respite means. One definition of respite care is that it’s the temporary, physical, emotional or social care of a dependent person that provides relief to the primary caregiver (Skilbeck, 2005). Perhaps the most inclusive discussion of the meaning of respite was given by Dr. M. Appleton (1995), in his book, *At Home with Terminal Illness: a Family Guide to Hospice at Home*:

A respite is a pause, a period of rest and separation for the patient and for the caregiver. It lets them both rebuild energy and stamina and gives both a break from stress. Everybody involved in the experience of dying becomes depleted—both physically and emotionally. The caregiver and the patient may require time to recuperate and gain perspective. They will then be better able to devote energy to the tasks that need doing at the end of life. Respite is essential. It is *not a luxury*. The East Indian poet Rabindranath Tagore once said, ‘There are two things which man cannot look at continuously, the sun and death’ (p. 80)

*Types of Respite Care Programs*

Respite care can take the form of many different ways and means to achieving the primary goal of meeting the bio-psycho-social-emotional needs of hospice caregivers. It is this important aspect of respite services for caregivers that I will focus on in this study; for without the respite caregiver’s contribution, the hospice program cannot succeed. As noted, many different types of programs exist
to ease the caregivers’ burden. This researcher will examine the local hospice agencies programs to determine how well they serve the respite care needs of this community.

In the U.K., which has a nationalized healthcare system, a range of respite services are offered in their specialist palliative care programs. These include inpatient care, day care, and different types of respite for the home-based hospice programs such as the MacMillan sitting service and the Marie Curie Support system, providing paid and volunteer practical and emotional support. Other interventions, such as social network and activity enhancement programs as well as group and individual programs for problem solving and education have been studied by researchers in an attempt to discern what the best way to help caregivers is. A recent cross sectional survey of Specialists Palliative Care Services (SPCS) and hospices in the U.K. demonstrated that a high proportion (80%) of them offered in-patient respite care intended to benefit both caregivers and patients (Skilbeck, 2005). Despite such extensive provisions, there still is a lack of sound, empirical evidence on respite in palliative care. The results of several researchers seem to imply that the evidence for unmet need is clear, but the development and evaluation of targeted interventions needs more investigation and research (Docherty, 2008; Harding, 2003; Skilbeck, 2005).

Another study from Australia looking at the carers’ perspective of the provision of respite care, found that carers most frequently identified respite care (35%) and help with household tasks (27%) as most important and needed. The amount of time identified for respite at home ranged from a few hours to a week (Zapart, 2007). Taking an interesting
and different approach, two separate studies, one in England and the other in Australia, looked at the evaluation of a night respite service. The Palliative Care Respite at Home Service (PCR@HS) in England offers a wide variety of respite care programs, ranging from regular visits to day care centers, in-home respite, or full-time short-term institutional care lasting between 2 and 6 weeks. But the care most utilized by families is oriented toward providing overnight support that allows family members the opportunity to sleep and feel refreshed to be able to take on their caring role in the daytime. These overnight visits are offered two to three times a week and are supplemented by two daytime visits as standard, however when death is imminent (the last 2 weeks of life), then night coverage becomes continuous (Green, 2006). In the second study, in Australia, the research aim was to develop a night respite needs assessment tool, implement a night respite care service and then evaluate the effectiveness of the service. Results showed the service to be of benefit to both the client, who had expressed a desire to die at home, and to the family who supported the request. Nearly 70% of the patients were able to die at home, resulting in a cost savings as well as meeting the physical, emotional and social needs of the family unit (Kristjanson, 2004).

In the U.S. the respite care services are not so varied nor well provided. Although Medicare lists inpatient care for respite as a benefit, studies has shown that a very small number of people (only 7% in 2000) utilize it. This limited use is consistent with other suggestions in the literature that Medicare’s reimbursement for such care is 61% lower than the average per diem cost of respite care (Carlson, 2000; Huskamp, 2001). In addition to this handicap to services; in order for a hospice to receive reimbursement for
respite care, the patient must be transferred to an inpatient facility. This process can cause tremendous stress and complications for the patient and family, impeding the use of any respite service. Currently, there are no home care respite programs reimbursed by Medicare. Figures from a 2007 study by the NHPCO reports even less respite care usage, 0.2% (NHPCO, 2008). It appears that most of the respite care provided in the U.S. comes not from professional sources, but from the hospice volunteers. Hospice is unique in that it is the only Medicare provider type that requires volunteer participation; at least 5% of total patient care hours must come from volunteers. While this amount of dedication and personal commitment to volunteerism is admirable, it fails to even come close to what is needed for adequate coverage. In fact in 2007, the average hours of service over a year’s time was 45.1 (NHPCO, 2008). Contrast this figure to that of respite care programs in other countries, where 24-40 hours per week are common, and the disparity is dismaying (Green, 2006).

The reason for the disparity is obvious when the reimbursement rates for respite care are examined. For the fiscal year 2009, inpatient respite care was $144.79 vs. routine home care at $139.97, a difference of about $5.00. Few facilities can offer care for the amount Medicare reimburses and stay in business, resulting in a situation where there are literally no adequate respite care services. Respite care can only be provided on an occasional basis as an inpatient and for no more than 5 consecutive days (Medicare Benefit Policy Manual, 2009).

When these financial realities are combined with the future estimates regarding population demographics of how we age, experience illness and die, the picture becomes
clearer that significant changes must occur, not only in respite care, but in the delivery of hospice services in general. As Baby boomers age and move into the arena of chronic illness and needing significant personal care, there will be fewer family members to provide that care. In part because they have fewer children and also because those children are more likely to live further away than was so in past generations. Women who have been the primary providers of such care are more likely to have careers outside the home and be unwilling or unable to quit their jobs to do so (Hallenbeck, 2003). Since home hospice depends so greatly on family caregivers to provide services, it’s apparent that the future success of these programs will depend on the creation of new approaches utilizing paid workers for both respite and primary care duties.

Changes in policies that would include increasing reimbursement for respite care in the home setting would be a great help. Then such innovative and helpful ideas such as the night respite programs could be implemented, utilizing home health aides to provide a lower cost per hour. Until that happens however, maybe a use of volunteer ‘vigil teams’ might be considered to ease the family caregivers burden during the last few days of life as a hospice in Arizona has done. These specially trained volunteers are closely supervised by a professional L.C.S.W. to provide a respite for patients and their families as death becomes imminent, staying at the bedside until the last hour and beyond to give support by their presence. Perhaps this researcher will discover other such creative and innovative practices to provide respite care in this community as this study of respite care programs unfolds.
Conclusions

This review of the professional literature has shown the history and the importance of hospice and palliative care services and how vital the contributions made by family members are to ensuring the successful enactment of their programs. There is a need to know more about this area of research, both locally and globally. As our population grows and the need for these types of services expands, it’s vital to have the information necessary to successfully implement those programs which can be most effective in achieving the organizations’ goals. It has been demonstrated that respite care services are essential to support the wishes of patients and families to die at home, peacefully and comfortably. Having the dignity of choice regarding the place of death is, or should be, a human right. The future of hospice in being able to provide for this choice will depend upon our willingness to provide the means to fund such programs.

It is always going to be hard to die, but when we have learned to accept death as an integral part of life, then we can learn to view it from a different perspective. It is through this acceptance of the natural order of life and death that we can understand our finiteness and can grow and become more of who we really are. When we truly understand that this day, this moment, may be our last, then we can create meaning and purpose in those moments. “There is no need to be afraid of death…it is the key to the door of life” (Kubler-Ross, 1975, p. 164).

On a personal note, this researcher experienced firsthand the opportunity to provide a home setting for a loved one’s wish to experience their death in an environment filled with meaning and peacefulness of body and mind. It was an unforgettable one that
inspired a desire to share this opportunity with others. Death can be indeed the door to growth and greater self-awareness.
Chapter 3

METHODS

Introduction

In this chapter the methodology used in this research study will be examined and explained. It begins with the description of the selected research design and why it was chosen as most appropriate for use and continues with a discussion of the variables of interest and participants. Next, the instrument used for data collection will be described in detail as well as the validity and reliability of the instrument and of the research itself. Data gathering procedures will be identified and a discussion of how the protection of human subjects was achieved. Finally, a description of data analysis will be presented to complete the discussion on methodology.

Design

According to Kreuger and Nueman (2006) in their research textbook, Social Work Research Methods, there are usually three purposes that can be used to classify any research project; exploratory, descriptive and explanatory. As the general purpose of the research guides the selection of the specific design, so it is that the design for this follows the exploratory and more qualitative approach of a non-experimental survey. There is little data currently available regarding respite care programs and how well they meet the needs of hospice patients and their families. More information is needed to determine what factors are important and impact on the research question. Strengths of this type of design approach to research include the ability to capture the richness and meaning from real world events and to use this information to inductively build theory that is grounded...
in the data. Limitations are that threats to internal validity are greater and more difficult
to control for. External validity is not possible as the non-random nature of data
collection is missing from this type of design.

Variables

In a qualitative study, there is no hypothesis or variables per se, however some
topics of interest are present. The variables of interest in this study include identification
of the particular programs at each hospice agency which address respite care needs for
their client population. Each respite care program will be assessed in terms of the
variables that comprise hospice respite care needs of patients and caregivers. These
include: strengths of existing programs in meeting emotional and physical needs of well-
being of clients, levels of client satisfaction, assessment of unmet needs and ideas for
future potential programs designed to meet those needs.

While these are all variables of interest for study; they are not considered
independent or dependent in nature. Likewise, there is no intervention to be implemented
in this study design. Identification of what services are available to individuals and their
families for respite care is primary to this study. The respite care needs include emotional
as well as physical needs for well-being of both patients and caregivers. The level of
client satisfaction with their experiences is another important concept for consideration in
this assessment. Finally, the identification and clarification of both unmet needs and ideas
for future possible solutions for those needs is useful information to gather for answering
the research question. The purpose of this study is to more fully explore the extent to
which local hospice agencies meet the respite care needs of the clients they serve. This
information can be useful for future considerations for the improvement and implementation of respite services that are more fully responsive to identified needs.

**Participants**

The participants in this study include the views of social work employees from the seven Medicare certified hospice agencies that comprise the Sacramento Hospice Consortium (Kaiser, Mercy, Sutter Auburn Faith, Sutter Visiting Nurses Association and Hospice, Roseville and Sacramento locations, UC Davis, and Yolo). The unit of analysis for this study is the view of social workers toward the existing respite care programs at the agency where they are employed. The sample is a non-random, convenience, snowball type. The manager of Sutter Roseville Visiting Nurse Association and Hospice, where this researcher interns, was the original contact for this sample. She recommended using the Sacramento Hospice Consortium Directory to gather names of other agency managers to contact for their permission to participate in this study. Those managers are asked to “snowball” other contacts within their individual agencies, i.e., the social workers employed there, for their willingness to participate in the survey. The size of the sample is estimated to be between 21-28 people, depending on how many people are employed at each hospice agency and their willingness to participate. This sample represents all the potential sources of information regarding hospice respite programs in the defined area of interest.

**Instrumentation**

The instrument used in this study is one created by the researcher specifically for this project and has the disadvantages of every such non-standardized instrument; it has
not been tested for reliability or validity. The reason it was used is that this researcher could find no other instrument in existence that would measure the variables of interest in this study. The instrument used for this study contains ten questions asking for specific information about respite care programs used at each agency. The first two questions are designed to obtain information regarding types of respite care and needs for improvement, and are open ended. The next three questions are to be answered using a Lichert scale for estimating how well the respondent believes the services meet the care needs of families, how many families needed respite and how many received it in the past month. The remainder are open ended questions asking for the opinion of the participant regarding utilization, strengths, problems and alternative ideas for improvement of services. (See Appendix for copy of survey).

Validity/Reliability

Since this study is a qualitative, exploratory survey design using a non-random sample of convenience with a snowball technique, the internal validity is limited as alternative explanations for results may exist. External validity is not present and so the results of this survey may not be generalized to any outside population.

The qualitative design of this study requires more emphasis on authenticity, i.e. the honest, fair viewpoint of the participants’ viewpoint or account of events than is possible with experimental research design. A qualitative approach is required by this topic due to the nature of the study population, the terminally ill. This is a population that is considered vulnerable to or at high-risk for sensitivity to the personal nature of questions regarding the dying process of a loved one contained in this graduate level
research study. This researcher, therefore is restricted to utilizing the professionals giving
the care, not the patients themselves, to determine whether or not those patients’ needs
are being met. This is fraught of course, with many opportunities for misinterpretation
and inaccurate information. As previously noted, it is also an area that has not been
studied and needs further exploration to simply gather basic information that can be used
for further, more detailed research. But the qualitative approach is very appropriate in this
case as it will provide a framework for developing concepts during data collection and
reexamining and reframing the important ideas that emerge. This inductive, interactive
route to information gathering will serve as a base of understanding for future researchers
to launch their more rigorous projects in the future.

Data Gathering Procedures

The source of participant contacts will include the seven hospice agencies that
comprise the Sacramento Hospice Consortium (Kaiser, Mercy, Sutter Auburn Faith,
Sutter Visiting Nurse Association and Hospice Roseville/Sacramento locations, UC
Davis, and Yolo). The contact information for these agencies from the Directory for
Sacramento Hospice Consortium members will be obtained from Sharyl Kooyer, RN,
Manager of Sutter Visiting Nurse Association and Hospice. The contact sources will be
the Director or Manager of each identified hospice agency. Initial contact will be by
email letter of introduction to agency directors requesting permission letter for study and
contact information for social worker subjects. After letter of permission received, all
social worker subjects will then receive an email letter of introduction/explanation with
consent form and survey attached for completion and return to researcher via email.
Research subjects will include all hospice social workers in each agency willing to participate in taking the survey (estimate of 3-4 per agency for a total of 21-28 people).

Protection of Human Subjects

In this study the protection of human subjects is followed by strict adherence to the University Guidelines for Protection of Human Subjects as outlined in Guideline A. Informed voluntary participation is insured through the use of a signed consent form that gave all participants detailed information regarding their choice to participate or not, without reprisal, in the study. Participants are informed of the time needed for the completion of the survey, the option to answer some, none or all of the questions and contact information for the researcher, thesis advisor and another resource for assistance if any need arose. The risk is described as none and the “Request for Review by the Committee for the Protection of Human Subjects” was submitted and approved by the University. Subject anonymity is insured by deleting identifying email addresses, storing results in a locked home office with a locked drawer inaccessible to anyone other than the researcher, separating the consent form from the surveys to avoid identification and destroying all data at the completion of the study. All data are reported in aggregate form so as to reveal no personal or identifying information about participants. Subjects are informed of the potential benefits to the social work professions body of knowledge regarding respite care and are offered no compensation for their participation.

Data Analysis

Since this is an exploratory study that is qualitative in nature, the information gathered is analyzed to provide an understanding of the research question with emphasis
on identifying patterns or creating themes that emerge from the data of the study. Then through a simple content analysis of documented evidence from the survey questions, a qualitative data base that estimates relationships between various concepts related to respite care programs and patient/family respite care needs is described.

Summary

This discussion of the methods used in this study includes a description of the research design and the reasons for choosing a qualitative, exploratory survey approach. In a field where little research has been undertaken, it is the most appropriate choice and will contribute to the future efforts of others yet to come. The participants and instrument utilized were clearly described with specifics pertinent to their selection outlined. Factors of reliability and validity limits as well as data gathering procedures were explained in detail. Next, the procedures undertaken for the protection of human subjects are listed and shown to be in compliance with the University requirements. Finally, a description of how the data is analyzed finished off the chapter, readying the reader for the upcoming discussion of findings.
Chapter 4

FINDINGS

Introduction

The purpose of this chapter is to discuss the findings of a survey questionnaire distributed to hospice social workers, eliciting their views regarding the respite care programs offered by their agency to their patients and families. Due to the qualitative nature of this study, the results presented are from subjective and objective analyses of the data that reveal emerging major trends and themes. Key findings are divided into four sections. The first section presents pertinent demographic information regarding participants and their agency programs for respite care. The second section discusses social workers views about how well the respite care needs of hospice families are being met. The third section explores utilization of respite services, the problems and strengths of respite programs from the social workers perspective. Finally, the fourth section presents the social workers thoughts on in- patient hospice facilities and their ideas for the improvement of respite care.

Findings

The respondents who participated in this study include 18 medical social workers employed at four different hospice agencies out of the total of seven that make up the Sacramento Hospice Consortium. Respondents’ length of time at work ranged from a minimum of five months to a maximum of 19 years.
Table 1

Demographic Characteristics of the Participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kaiser</td>
<td>7</td>
<td>39</td>
</tr>
<tr>
<td>Sutter Roseville</td>
<td>4</td>
<td>22</td>
</tr>
<tr>
<td>Sutter Sacramento</td>
<td>4</td>
<td>22</td>
</tr>
<tr>
<td>Yolo</td>
<td>3</td>
<td>17</td>
</tr>
<tr>
<td>Years of Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 or less</td>
<td>3</td>
<td>17</td>
</tr>
<tr>
<td>2-5</td>
<td>8</td>
<td>44</td>
</tr>
<tr>
<td>6-9</td>
<td>5</td>
<td>28</td>
</tr>
<tr>
<td>10 or more</td>
<td>2</td>
<td>11</td>
</tr>
</tbody>
</table>

The types of hospice respite care programs offered by each agency include:

1) One five-day respite care admission at a skilled nursing facility per benefit period

2) Volunteer programs using trained volunteers to provide 4 hrs per week

3) Hired caregivers and Medi-Cal program In Home Support Services workers

In addition, Kaiser Hospice offers a program to include 16 hours of paid care in the home per benefit period (90 days for two periods, then subsequent 60 day periods) or roughly .75-2.0 hours per week.
Table 2

*Types of Care*

<table>
<thead>
<tr>
<th>Types of respite care</th>
<th>Frequency used</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 Day respite in skilled nursing facility</td>
<td>18</td>
<td>100</td>
</tr>
<tr>
<td>Volunteer Program</td>
<td>8</td>
<td>44</td>
</tr>
<tr>
<td>16 hour in home caregiver paid by agency</td>
<td>7</td>
<td>39</td>
</tr>
<tr>
<td>Private pay/IHHSS caregiver</td>
<td>4</td>
<td>22</td>
</tr>
</tbody>
</table>

A careful analysis of the data showed no relationship between years worked, or types of respite care programs utilized by the subjects. As shown, all respondents used the five-day respite benefit for admission to a skilled nursing facility and all the Kaiser employees used the 16 hour benefit for paid caregivers in the home. The second most preferred respite program used was the volunteer program, with nearly half of all subjects responding positively.

The next section’s discussion finds some interesting data for interpretation, namely the relationship of social workers perceptions of patient needs and how often those needs were met by the respite care programs available. The Lichert scale used in the survey question was ranged from Very Well, Well, Adequate, Not Very Well and Poor. The responses were nearly split with 11 subjects answering Very Well/Well, and eight subjects answering Adequate/Not Very Well with no Poor responses. The only Very Well responses came from Kaiser Employees who utilized their agencies’16-hr paid caregiver benefit, suggesting that this respite program option has great perceived benefit.

The major theme that emerged from studying the data revealed that in every case without exception the single most significant factor in respondents’ view of how well their agency met the needs of its patients was how often the need perceived was met. In
every case when the respondent answered Not Very Well, the assessed need for service exceeded the care received, in most cases by a 1:2 ratio. In these cases, the perceived need for respite was 10-20 or more and the met need with services received was 1-9 or roughly half of the time. Conversely, with the respondents who answered Very Well/Well, the rates of need assessed and met was equal each time. These data sets were equally dispersed between employment sites, length of employment, and types of programs available for use. So, it appears that when evaluating the respite programs at their agency, what mattered most in creating a positive result was the social workers perception of how often the assessed need for services was met. A total of five subjects responded None to the question of how many patients needed respite care.

The third section now looks at the reasons why social workers believe respite care programs are not being utilized and the problems and strengths of those programs. The professional literature reflects the information gathered from survey respondents; namely that great ambivalence has been identified among family caregivers if respite is not offered in the home setting and high regard for self reliance and independence (Harding, 2003). In this study, 12 respondents wrote their related explanations for why services aren’t being used by families. These reasons included: (a) Devoted and close emotional family bonds, (b) a belief system that spouse and daughters, in particular, were duty bound to provide care themselves, (c) guilt and regret if respite outside the home was used and the patient died sooner, and d) a fear of strangers overseeing care. In four other subject responses, the negative impression of skilled nursing facilities and promises made to the dying to keep them at home were listed. As reasons for not utilizing respite
services, a trend toward patient and family preference for home care and as a location for death was seen in 12 out of 18 responses indicating that in a majority of cases, 67%, these social workers views mirror information found in the literature; i.e. most people want to die at home (Higginson, 2004).

Despite the aforementioned patient and family preferences for home care, the identified problems that emerged from the data reflected issues that related to skilled nursing home five-day respite programs. The theme here was mainly focused on not enough beds available geographically close to patients home and the difficulty of managing paperwork policies and procedures for admission, although caregiver guilt and undesirability of nursing home environment was mentioned twice by respondents.

The strengths reported were linked to social workers beliefs in their own abilities and skills in providing resources to families in need; seven subjects’ responses indicated their expertise was the greatest strength. The availability and effectiveness of the volunteer program was listed in five cases and the five-day respite in a skilled nursing facility in four.

This fourth and final section discusses the social workers thoughts on usage of a home style inpatient hospice facility and their ideas for the improvement of respite care programs. The greatest need for improvement was identified by one subject as the need to increase awareness and information about hospice and palliative care; echoing this researcher’s earlier discussion of the impact of cultural factors that influence this problem. In a unanimous response, all 18 respondents agreed that an inpatient facility for hospice respite was a desirable option. The major theme underlying these responses was
also reflected in their ideas for improvement, namely, that patients and their families prefer home-like settings if home itself is not an option and such a facility could relieve the caregivers of their guilt and fear when 24 hour professional care is available to the dying in a specialized care facility.

The social workers ideas for improvement were similar to this same theme; four responded to the need for an inpatient facility, nine subjects thought the ability to use Residential Care Facilities (Board and Care Homes) and the patient’s own home with hired caregivers would be useful, and 6 respondents identify the need for more respite beds in skilled nursing facilities closer to home. All of these ideas are ways to be able to come closer to meeting patient and family needs and desire for respite care that respects their individuality and promotes a good quality of life.

The problems encountered in obtaining this sample were initially the approach was to have been in person, meeting hospice agency directors at a scheduled meeting of the Sacramento Hospice consortium in October 2009. However, due to a lack of attendance that meeting was cancelled and did not meet again until January 2010. This meant a significant delay in proceeding with the study and may have contributed to this researcher’s ability to survey all seven hospice agencies. This researcher’s original plan was to survey social workers from all seven agencies and have a sample size of between 21-28 subjects. However obtaining agency permission became an obstacle to success as some hospice agencies were unable or unwilling to obtain permission from administrative authorities due to their own facilities policies for the protection of human subjects.
The four hospice agencies represented in this survey include Sutter Roseville, Sutter Sacramento, Kaiser and Yolo.

Difficulties also emerged in the original methodology with attempting to use email as a vehicle for data collection. Due to the need for participant consent form signatures and original letterhead stationary for agency permission letters, much of the data collection was done in person during agency staff meetings and in the case of Yolo Hospice, by U.S Postal service.

Summary

In this chapter, a discussion of the results of a survey given to 18 medical social workers employed by four local hospice agencies revealed their personal viewpoints on how well the hospice respite care needs of their clientele were being met. Included in this discussion were demographic data regarding the sample and their agencies, social workers views on the efficacy of their agencies programs, identified problems and strengths as well as utilization of those services and thoughts on inpatient hospice facilities and ideas for improvement of respite programs.

The major findings are that years worked and types of respite programs utilized by the subjects are not related to one another in any particular way. The most common program utilized for respite is the five-day skilled nursing benefit with volunteer programs second in usage. Despite variation in programs available to subjects, i.e. a 16 hour paid caregiver benefit to Kaiser Clients, the single most significant factor influencing social worker opinion of how well respite needs are being met is the degree to which the assessment of need meets actual need met. When assessed need is congruent
with need met, then the respondent felt that their programs were effective and rated them in the top two highest rankings. Eleven subjects responded that their respite programs met the needs of clients either Well or Very Well, while eight rated their respite programs as Adequate or Not Very Well, there were no Poor responses. Although all subjects listed five-day respite in a skilled nursing facility as a respite choice, they also responded that there are many problematic issues. These types of settings are not homelike in nature; many patients and families have very negative reactions to using them and they are not located close to where patients reside and have too few beds to offer. A majority of social workers, 67%, cite the patient and families desire to stay in the home as a significant reason for not utilizing this benefit. Another major finding is that all participants agreed that having an inpatient hospice facility would benefit respite care greatly and better serve individualized patient and family needs and wishes. Ideas for improvement of respite services expanded on this theme of patient and family choice for home settings by extending the five-day respite benefit to include the patients’ home and the more homelike settings of Residential Care Facilities or Board and Care Homes.

An unexpected finding included the social workers response that their own professional interventions were the greatest perceived strengths of the respite programs with volunteer programs next. It was also interesting to note that while social workers agreed that skilled nursing homes were far from ideal choices, they were uniformly utilized, perhaps due to the reality of having no other options in most cases. More discussion of these and other findings as well as conclusions and implications for practice and recommendations for future research follow in the next and final chapter.
Chapter 5

CONCLUSIONS AND IMPLICATIONS FOR SOCIAL WORK

Introduction

This chapter contains a review of the findings from the study and explains how relevant findings were in answering the question of how well hospice respite care meets the needs of the community. A discussion of conclusions drawn and an interpretation of the results are presented to offer some possible explanations. Included in this discussion are the implications for social work practice as well as the problems and limitations encountered. Finally, recommendations for future researchers are shared.

Review of Findings and Relevance

The minor findings of this study suggest that information about demographic characteristics, such as years of employment and specific agencies of employment, have no relationship to any other data. The most common type of respite care program utilized by all social workers is the 5–day respite benefit in a skilled nursing facility and when available, the 16 hour in-home caregiver benefit paid for by the agency. The use of these respite programs is relevant in two ways. The use of in-home caregiver services clearly reflects the preference of patient and family’s choice to receive care at home. The literature abounds with studies verifying this finding. The relevance of utilizing skilled nursing homes is simply that there is no other option in our community for placement, as residential care homes or private residences are not currently eligible for respite assistance that is reimbursed by insurance companies. The finding on why social workers believe respite care is underutilized reflects this problem; most people are not choosing
admission to a skilled nursing home if they can afford any other option. Many families are insistent on caring for loved ones themselves and will not accept any help if it is outside the patient’s home setting. This can lead to caregiver burnout and as demonstrated in the literature, valid concerns that not only are caregiver’s needs for respite care unmet, but the patient’s wish to die at home are impossible to achieve (Harding, 2003).

The second most popular program for respite, 8 out of 11 responses, is the use of volunteers to provide a 4 hour weekly time for patients and their families. The relevance of this program and its frequency is that once again, it allows people to stay in their homes while receiving respite care.

The major findings of this study relate to the social workers views of how well respite care needs were met by their agencies. Interestingly, the answer is very dependent on whether the social workers perceived assessment of need, was met or not met. The relevance of this rather surprising data is the unexpected influence of personal values and judgments by individual social workers. Even when special programs exist (i.e. the 16 hour paid caregiver benefit) it is not as significant as the individual social workers evaluation. Another response is relevant here, the response that there were no instances when respite care was needed. Without more information on the number of total assigned cases and length of stay in hospice care, it is difficult to know for certain how to interpret these 5 responses of None.

The final data that represented a unanimous approval response was the question regarding an inpatient hospice facility for use in respite care. All 18 subjects believed in
the need for such a facility to provide home styled professional respite care where patients and their families could be comfortable when home itself is not an option. Many authors, from the early pioneers of hospice philosophy such as Elizabeth Kubler-Ross (1975) to Cicely Saunders (2000) and into the present day, are staunch advocates of inpatient hospice care where palliative services can create an atmosphere conducive to dying with dignity and in peaceful surroundings. In addition to this idea for improvement of hospice respite services, the other ideas expressed by respondents, also reflected concern for patients voiced desire to be at home or in homelike settings, such as residential care homes or their own private residences with hired caregivers paid for by insurance sources.

Implications

This study has verified what the literature described in many ways. First of all, it has contributed some much needed data to the field of information regarding the needs of patients and their families for respite care programs and perhaps more importantly, what those programs should look like. The social work field has as its primary purpose advocacy for basic human rights and the enhancement of human well-being, particularly that of those who are vulnerable. Surely the dying are worthy of our attention as we seek new ways to meet the needs of one our most vulnerable populations. It is this researcher’s hope that this study will at the least, spark interest in efforts at opening an inpatient hospice respite care facility, one that could be shared by all the hospice agencies in this community with costs shared as well.
Recommendations for Further Research

One of the problems encountered in this study was the difficulty in obtaining agency permission from some agencies to conduct the survey. Initially, the Sacramento Hospice Consortium was used as a point of contact, but in reality this was not too effective as directors don’t attend the meetings, so no contact was made with the directors at these meetings. This researcher now believes that surveying all hospices in the community might have made a difference in succeeding with more subjects to survey. There are several local private hospice agencies that might have been more willing to participate as their management and ownership is more accessible.

The survey questions could be improved by including questions regarding gender and also designed to find out the number of cases handled each month and the length of stay for those cases. This type of information would be very helpful in interpreting data.

The next logical study to do in this area is to survey or interview hospice patients and their families. They would be able to voice their needs and desires directly and the social workers assessment variability would not be an issue. In this way, needs and patient preferences for programs to meet their needs could be delineated and the information used in helpful ways to design new and more useful programs.

Summary

This study looked at the question of whether hospice respite care programs in the community are meeting the needs of dying persons and their families from the social workers perspective. The major findings of the study were that about half (or 11 out of 18 responses) of the social workers felt they were successful in meeting respite needs. But
this data was compromised by the fact that it was completely subjective according to social workers personal judgments and opinions regarding assessment of need and need met. What is clear and inarguable is the need for a local inpatient hospice respite facility for community use. Other improvements, at lesser cost, need to be implemented as well in order to meet the respite care needs of the dying and their families, notably more home based, home-style alternatives to the skilled nursing home benefit that is the sole choice currently. There are many possible solutions to improving respite care in our community and it is this researchers dream to be involved in the future developments yet to come.
December 1, 2000

To Whom It May Concern:

Randy Neblett, MSW Student at CSUS, has contacted me regarding her interest in work on a research study focused on respite care services of hospice agencies in Sacramento.

The Sacramento Hospice Consortium is comprised of the seven not-for-profit hospices in the greater Sacramento Area. As Coordinator of the SHC I am able to provide access to the member programs, although each program operates autonomously, and thus I am not in a position to guarantee or authorize their participation.

I have invited Randy to a Consortium meeting in January when she will be able to meet Directors and Volunteer Coordinators from the various programs and present her project. I will also provide her with a roster so that she may contact each program directly.

Sincerely,

Cindy Dunlap
Coordinator

The Sacramento Hospice Consortium is a California Non-Profit Organization
Sutter Auburn Faith VNA & Hospice • Kaiser Hospice • Mercy Hospice
Sutter VNA & Hospice, Roseville • Sutter VNA & Hospice, Sacramento
UC Davis Hospice • Yolo Hospice
APPENDIX B

Kaiser Letter of Permission

February 11, 2010

To Whom It May Concern:

I have been contacted for permission to participate in a research study conducted by Randy Neblett, MSW II Student at CSU, Sacramento regarding information about the respite care services provided by agencies in the Sacramento Hospice Consortium. It is my understanding that this study will consist of a 10 question survey administered to the professional social workers employed by this agency to determine how well the respite care needs of our clients are being met by the current respite programs. This survey will take approximately ten minutes to complete.

I have been informed that there is no anticipated risk to participants as questions are related to their professional work and the performance of daily activities for which education and professional training have been given. No personal questions were included. I have received a copy of the informed consent and survey forms to be used by the participants in the study.

I agree to allow Randy Neblett, MSW II Student at CSU, Sacramento to attend our MSW Meeting and discuss this study. In addition to obtain permission from each social worker to complete the survey.

I give my permission for this agency and its designated employees to participate in this research study as described.

Sincerely,

[Signature]

Jennette Salinas, LCSW/CT
Social Work Supervisor/Bereavement Services
Kaiser Hospice, North Valley & South Sacramento
916-977-3197
APPENDIX C

Yolo Hospice Letter of Permission (1)

January 21, 2010

To Whom It May Concern:

I have been contacted for permission to participate in a research study conducted by Randy Neblett, MSW II Student at CSU, Sacramento regarding information about the respite care services provided by agencies in the Sacramento Hospice Consortium. It is my understanding that this study will consist of a 10 question survey administered to the professional social workers employed by this agency to determine how well the respite care needs of our clients are being met by the current respite programs. This survey will take approximately ten minutes to complete and will be conducted via email communication.

I agree to release pertinent email/phone contact information for her use to access the social workers at this agency in order to conduct the survey. I have been informed that there is no anticipated risk to participants as questions are related to their professional work and the performance of daily activities for which education and professional training have been given. No personal questions were included. I have received a copy of the informed consent and survey forms to be used by the participants in the study.

I give my permission for this agency and its designated employees to participate in this research study as described.

Sincerely,

Suzanne Trygar, MSW
Social Work and Chaplaincy Manager/Agency Representative
APPENDIX D

Yolo Hospice Letter of Permission (2)

Attachment A: Letter of Permission

To Whom It May Concern:

January 22, 2010

I have been contacted for permission to participate in a research study conducted by Randy Neblett, MSW II Student at CSU, Sacramento regarding information about the respite care services provided by agencies in the Sacramento Hospice Consortium. It is my understanding that this study will consist of a 10 question survey administered to the professional social workers employed by this agency to determine how well the respite care needs of our clients are being met by the current respite programs. This survey will take approximately ten minutes to complete and will be conducted via email communication.

I agree to release pertinent email/phone contact information for her use to access the social workers at this agency in order to conduct the survey. I have been informed that there is no anticipated risk to participants as questions are related to their professional work and the performance of daily activities for which education and professional training have been given. No personal questions were included. I have received a copy of the informed consent and survey forms to be used by the participants in the study.

I give my permission for this agency and its designated employees to participate in this research study as described.

Sincerely,

Douglas K. Jena
Executive Director
APPENDIX E

Sutter VNA & Hospice Letter of Permission (1)

November 18, 2009

To Whom It May Concern:

I have been contacted for permission to participate in a research study conducted by Randy Neblett, MSW Student at CSU, Sacramento regarding information about the respite care services at Sutter Roseville VNA & Hospice. It is my understanding that this study will consist of a 10 question survey administered to the professional social workers employed by this agency to determine how well the respite care needs of our clients are being met by the current respite programs. This survey will take approximately ten minutes to complete and will be conducted via email communication.

I agree to her use of the Sacramento Hospice Consortium Directory for contact information for the Director. I agree to release pertinent email/phone contact information for her use to access the social workers at this agency in order to conduct the survey. I have been informed that there is no anticipated risk to participants as questions are related to their professional work and the performance of daily activities for which education and professional training have been given. No personal questions were included. I have received a copy of the informed consent and survey forms to be used by the participants in the study.

I give my permission for this agency and its designated employees to participate in this research study as described.

Sincerely,

Sharyl Kooper
Hospice Clinical Manager
November 18, 2009

To Whom It May Concern:

I have been contacted for permission to participate in a research study conducted by Randy Neblett, MSW Student at CSU, Sacramento, regarding information about the respite care services at Sutter Sacramento VNA & Hospice. It is my understanding that this study will consist of a 10 question survey administered to the professional social workers employed by this agency to determine how well the respite care needs of our clients are being met by the current respite programs. This survey will take approximately ten minutes to complete and will be conducted via e-mail communication.

I agree to her use of the Sacramento Hospice Consortium Directory for contact information for the Director. I agree to release pertinent e-mail/phone contact information for her use to access the social workers at this agency in order to conduct the survey. I have been informed that there is no anticipated risk to participants as questions are related to their professional work and the performance of daily activities for which education and professional training have been given. No personal questions were included. I have received a copy of the informed consent and survey forms to be used by the participants in the study.

I give my permission for this agency and its designated employees to participate in this research study as described.

Sincerely,

[Signature]

Sharyl Kooyer, RN
Hospice Clinical Manager
APPENDIX G

Human Subjects Application

CALIFORNIA STATE UNIVERSITY, SACRAMENTO
Division Of Social Work

TO: Randy Nebbett
FROM: Committee for the Protection of Human Subjects

RE: YOUR RECENT HUMAN SUBJECTS APPLICATION

We are writing on behalf of the Committee for the Protection of Human Subjects from the Division of Social Work. Your proposed study, "Community Assessment of Hospice Respite Care Programs:"

_X_ approved as ______EXEMPT  X_ NO RISK  ____MINIMAL RISK.

Your human subjects approval number is: 09-10-064. Please use this number in all official correspondence and written materials relative to your study. Your approval expires one year from this date. Approval carries with it that you will inform the Committee promptly should an adverse reaction occur, and that you will make no modification in the protocol without prior approval of the Committee.

The committee wishes you the best in your research.

Professors: Telesha Bankhead, Chrys Barranti, Andy Bein, Joyce Burris, Maria Dimis, Susan Eggman, Sue Lee, Kishan Na, Sue Taylor

Cc: Dr. Joyce Burris
APPENDIX H

MSW Letter

Jan. 18, 2010

Dear name of MSW,

The professional literature regarding hospice respite care needs and services indicates that more information is needed for future studies. As a social work professional in the field of hospice, your input will be invaluable to this research project designed to gather information regarding respite care services at your hospice agency. I would like to invite your participation in a short survey requiring 10-15 minutes to complete. Permission has been granted by your agency to conduct this study and your participation would be greatly appreciated. I am a second year Master’s in Social Work student from CSU Sacramento, working as an intern this year at Sutter Roseville VNA & Hospice in Roseville and have become very interested in how our community meets the respite care needs of its members.

Please consider taking the 10-15 minutes it will take to sign the consent form and complete the short questionnaire in order to contribute to the profession as a whole. The consent form and survey can be mailed to me using the enclosed SASE. Your ideas for improvement of services are especially valued. Any questions or concerns may be directed to me or my thesis advisor listed below. Thank you in advance for your time and cooperation.

Randi Neblett, R.N., B.S.N., MSW Intern
CSU Sacramento

Thesis Advisor: Dr. Joyce Burris

Sutter Roseville Hospice: (916) 797-7850 - ext.5847
Home: (916)409-0450/ cell : ( 916)316-2756
rrneblr@sutterhealth.org

burris@csus.edu

(916)278-7170
APPENDIX I

Informed Consent For Participation

Purpose:
This study is part of a research project for a Master’s in Social Work program at CSU Sacramento, conducted by Randy Neblett, MSW II Intern, looking at how our community meets the respite care needs of hospice families. The thesis advisor for this study is Dr. Joyce Burris. As a hospice social worker you have experience and knowledge regarding respite care programs that is essential for successful completion of this study.

Procedures:
Information will be collected using a survey questionnaire distributed to social workers in agencies comprising the Sacramento Hospice Consortium. The 10-question survey will consist of an intake with each social worker of the hospice care team at your agency. It will take approximately ten minutes to complete.

Compensation:
There is no compensation involved in this study.

Confidentiality/ Right to Withdraw:
Your participation in this study is strictly voluntary; you are free to stop participation at any time. You may decline to answer any or all questions with no negative consequences resulting. All data will be reported in aggregate form so as to reveal no personal or identifying information of participants. The information collected will be kept strictly confidential at all times as surveys will be conducted anonymously. Surveys will be stored separately from consent forms to avoid identification and all data collected will be stored in a locked drawer inaccessible to anyone other than this researcher and destroyed at the end of the study.

Risks/Benefits:
There is no risk for participants as questions are related to professional work and daily activities. No personal questions will be asked. The benefits from participating would be the satisfaction of contributing to the professional body of knowledge regarding respite care programs and their future improvement.

If you choose to participate, please sign and return this form and the completed survey as soon as possible. Your participation is highly appreciated and will help contribute to greater knowledge in the field of hospice care respite.
Contact Information:

Randi Neblett, R.N., MSW II Intern
CSU, Sacramento
burris@csus.edu
Email: rrneblr@sutterhealth.org
Sutter Roseville Hospice: (916) 797-7850 ext. 5847
(916) 409-0450/316-2756

Thesis Advisor: Dr. Joyce Burris
(916) 278-7179

YES, I am interested and consent to participate in this study.
Signature: ___________________________________________

Agency/Title: _______________________________________

Thank you very much for your time and attention.
APPENDIX J

Survey Questionnaire

1. How long have you worked at this hospice agency?

2. What respite care services are currently offered by your hospice agency?

3. How well do the respite care services at your agency meet the needs of your hospice families?

<table>
<thead>
<tr>
<th>Very Well</th>
<th>Well</th>
<th>Adequate</th>
<th>Not Very Well</th>
<th>Poor</th>
</tr>
</thead>
</table>

4. How many hospice families in the past month have needed respite care services?

   | 20 or more | 10-20 | 1-9 | None |

5. How many received respite care services?

   | 20 or more | 10-20 | 1-9 | None |

6. Why do you think existing respite care programs are not being utilized?

7. What do you think are the strengths of your respite care services?

8. What are the biggest problems (e.g. challenges, difficulties, frustrations) of your respite care programs?

9. Do you believe that a home style inpatient hospice facility, if available, would be utilized and feasible? Why or why not?

10. What do you think are the greatest needs for improvement in respite care services? What ideas do you have for improvements? Please be specific and as detailed as possible.
APPENDIX K

Contact Letter to Hospice Agency Managers

Revised 1/09/10

This letter follows an email communication sent to you on 12/19/09, inviting your participation in a research project designed to gather information regarding respite care services from the hospice agencies comprising the Sacramento Hospice Consortium. I am a Master’s in Social Work student intern at CSUS, working this year at Sutter Roseville VNA & Hospice and have become very interested in how our community meets the respite care needs of its members. I have a deep appreciation for the challenges and difficulties faced by hospice families. All information gathered will be treated as strictly confidential and any conclusions about the study will remain anonymous. A Letter of Permission is required by the Human Subjects Committee at CSUS for participation in this study and the template for that letter is enclosed along with a SASE for return to this researcher. Should you consent to participate, I will need phone and email contact information to survey the social workers in your agency. The forms for consent and the survey for the social workers are attached to this letter for your information. If you are willing and able to participate in this research study, I will need the permission letter returned as soon as possible. Thank you for your consideration of this request. If you have any questions or would like to discuss this further, please contact me directly at:

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REFERENCES


