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IMPACTS OF THE CAREGIVING EXPERIENCE ON THE CAREGIVER

A Project

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

---

by

Nayeli Corona

June 2010

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Approved by:

[redacted]
Dr. Rosemary McCaslin, Faculty Supervisor
Social Work

6/1/10
Date

[redacted]
Dr. Janet C. Chang,
M.S.W. Research Coordinator

ABSTRACT

This study explores the impacts of the caregiving experience on caregivers who provided care to an individual faced with a terminal illness. The study builds on the existing qualitative and quantitative literature that examines the demands and stressors caregivers undergo as a result of their time caring for a loved one. A qualitative approach was used in this study to interview seven participants. The sample included four male and three female caregivers. The outcome of the interpretive and narrative analysis resulted in five themes. The findings of this study indicated that overall caregivers found satisfaction in their caregiving efforts, and found comfort in knowing they did everything they could for the care recipient while they were alive. Implications and recommendations for future research are discussed.

ACKNOWLEDGMENTS

I would like to thank my parents, Leticia and Eduardo Corona, for all the hard work and sacrifices they endured so that I could pursue my academic endeavors. I am forever indebted to them and will never take for granted the gifts of love, education, and hope they have bestowed upon me. I would also like to convey my most heart-felt appreciation for my siblings, Denise and Eddie; my life's journey would not be the same without you. I am also obliged to thank Jonathon Zitney for the support and academic encouragement he has provided me throughout the years.

I would be remiss if I did not express my appreciation to Dr. McCaslin for her guidance in this study. I would also like to acknowledge Lorraine Hedtke, MSW, ACSW, LCSW, for enriching my professional life by instilling in me a curiosity in narrative practices.

This study could not have been possible without the participation of the seven caregivers who agreed to share their experiences as caregivers, and opened their hearts while sharing their experiences and memories of their loved ones. I honor each and every one of them for their

achievements as caregivers and appreciate their willingness to be part of this study.

I would also like to thank the California State University San Bernardino (CSUSB) Social Work Department for allowing me the opportunity to fulfill my academic goals in this reputable program. Lastly, this thesis would not be complete without expressing my gratitude to the members of my cohort who accompanied me in this two-year journey. My most sincere thank you to family and close friends that have been there for me when I needed them.

DEDICATION

This study is dedicated to the life and memory of my grandfather, Jose Aguila. My grandfather endured years of challenges as a result of living with diabetes. However, despite this setback he always accepted what came his way and never became bitter or resentful of anyone or anything in life. His kindness and warm smile are forever embedded in my memories.

This study is equally dedicated to my mother, Leticia Corona, and grandmother, Guadalupe Aguila Meza. Both are amazing women whom provided my grandfather the most dedicated loving care I have ever witnessed. The care my mother and grandmother provided to my grandfather was the catalyst and inspiration for this study. This world has been a better place due to the influence of these three individuals.

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CHAPTER ONE

INTRODUCTION

Problem Statement

According to Schmiedling (2006), the term "caregiving" denotes supportive, mostly low-tech services, such as bathing or feeding. The term is also commonly associated with administering medical aid, such as providing medications and attending to wounds. Also relevant is the term "informal care," which The Family Caregiver Alliance (2006) states is often used to refer to care given by individuals who do not receive compensation, such as family members or friends. The latest estimates by the Family Caregiver Alliance (2006) suggest that there are approximately 52 million "informal" caregivers who provide care to someone who is terminally ill or disabled. Furthermore, the Family Caregiver Alliance (2006) asserts that unpaid family caregivers will continue to be the leading long-term care providers in the U.S. for many years. In fact, given the dynamics of population growth it is projected that the already large volume of family caregivers will increase by 85% from the year 2000 to 2050.

Bengston (2001) states that although informal care is not a novel development, social changes, which are in part related to medical advances, have increased the demands on the caregivers. This increased demand has required caregivers to provide multifaceted care for longer periods of time (Bengston, 2001). According to Arno (2006), family caregivers on average provide care for a minimum of 21 hours per week. For many caregivers, this weekly workload continues for more than four years, with 33% of caregivers providing care for five years or longer.

It is widely believed that at least 50% of caregivers assist with one or more activities of daily living (ADL). These activities may include helping the care recipient to get in and out of bed, dress himself/herself, or assist with sitting and standing. Additional estimates also suggest that 80% of caregivers assist with transportation, grocery shopping, and housework (National Alliance for Caregiving & AARP, 2004).

The demands, challenges, and inevitable stressors that are so often part of the roles of a caregiver often result in what is referred to as caregiver burnout. For a significant number of caregivers the sources of stress derived from caregiving are linked to three primary areas. According to Hooyman and Kiyak (2008), these areas include (a) financial costs, (b) physical and mental strain (which due to the overwhelming focus on the needs of the care recipient often leads to self-neglect on behalf of the caregiver), and emotional demands and stress. According to the National Alliance for Caregiving and AARP (2004), emotional costs tend to increase with increased levels of care. Furthermore, Seligson (2009) states that caregiver burnout can be analogous to post-traumatic stress syndrome in that an individual may begin to exhibit symptoms months after a traumatic episode occurs. This implies that a caregiver may still be at risk of experiencing caregiver burnout well after his/her role as a caregiver has concluded.

In addition to the stress and demands of caregiving that informal primary caregivers face, it is of great importance that caregivers' own grief and bereavement process be understood and addressed by the caregiver. Waldrop (2007) indicates that caregivers experience multiple losses during the period of declining health of a loved one diagnosed with a terminal illness. A study by

Waldrop (2007) suggests that caregiver grief during the end-stages of care could be described as a state of heightened responsiveness, which includes anxiety, depression, nervousness, restless feelings, fear, and tension. Caregivers at this stage were also characterized as having trouble remembering events, had difficulty concentrating, and otherwise had difficulty completing common tasks.

Understanding the grief and bereavement issues caregivers face is vital to the profession of social work because this population is one to with which many hospice social workers and others interact on a daily basis. Social workers must address these issues from both a macro and micro oriented perspective in order to adequately meet the needs of such caregivers. Informal caregiving, according to Arno (2006), saves the American healthcare system an estimated $306 billion in health care costs per year. Legislative measures, such as the National Family Caregiver Support Program (NFCSP) created in 2000, have also helped support informal primary caregivers. Services provided under the NFCSP assists caregivers at both a macro and micro level. The NFCSP program mandates that the following services be provided:

(1) respite care, (2) individual counseling, and special caregiver training and other supplemental services based on the caregiver's needs. Depending on a particular agency's financial resources, social workers can also address caregiver needs through the utilization of psycho-educational classes and other resource referrals. In addition, social workers also facilitate caregiver support groups as well as bereavement groups and respite-based interventions.

Purpose of the Study

The purpose of this study was to examine the experiences of primary caregivers who have provided care to someone who is terminally ill. The study explored various elements such as financial costs, physical demands, and emotional strain that are all believed to be contributing factors in the caregiver's stresses encountered during caregiving (Hooyman & Kiyak, 2008). Since the quality of treatment of the care recipient relies so heavily on the well-being of the primary caregiver, it cannot be stressed enough how important it is to assess and explore the multifaceted demands that caregivers face.

This study aimed to examine the experiences caregivers go through while providing care to someone who is terminally ill. The goal was to expand current understanding regarding caregiver experiences. The study employed qualitative interviews to examine the complexity of the experiences of the surviving primary caregiver. To be included in the study, participants must have provided care to someone who was terminally ill within the past three years. Participants in the study will be asked to take part in semi-structured interviews, which will be recorded and later transcribed.

Significance of the Project for Social Work

This study is significant for the social work profession because it helps identify the various afflictions that informal primary caregivers are faced with while undertaking the task of caring for someone who is terminally ill. It is hoped that this study will raise awareness of the challenges and needs of informal caregivers.

This study incorporates the values that guide the social work profession. The preamble provided by the code of ethics of the National Association of Social Work (NASW) states that its primary mission is to

> enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty. A historic and defining feature of social work is the profession's focus on individual well-being in a social context and the well-being of society. Fundamental to social work is attention to the environmental forces that create, contribute to, and address problems in living. (NASW, 1996, para 1)

This study seeks to increase the knowledge base and awareness relating to caregiver's experiences and needs in order to increase the competence level of social workers. The hope is that the findings of this study will bring into focus the existing needs of caregivers and the corresponding gaps in services intended to address those needs. This study intends to facilitate the creation of effective interventions that will benefit and increase the quality of life of caregivers.

The results of this study hopefully will impact the attention given to caregivers by medical staff and other agencies that work with primary caregivers of those who are terminally ill. Ideally, this study will emphasize the ways in which caregivers experience grief both before and after the care recipient has passed away. Such emphasis will shed light on the difficulties and struggles caregivers undergo in re-adjusting to their new role, which ultimately must include moving on in life without the terminally ill individual.

CHAPTER TWO

LITERATURE REVIEW

Introduction

There is a significant amount of existing literature which corroborates the importance of this study and which elaborates on the integral nature of the issues addressed herein. For example, there is a substantial amount of research regarding caregiver burnout. The existing literature which discusses the experiences, demands, and impact of caregiving will be presented in the following subsections: (1) caregiver stress and demands, (2) implications of gender in caregiving, (3) caregiver grief following a terminal illness, and (4) bereavement and the theoretical framework guiding conceptualization.

Caregiver Stress and Demands

While many may think that the majority of long-term care is conducted by nursing homes, such a belief is inaccurate. The reality is that an estimated 80% of long-term care is provided by private and informal caregivers such as family members (Hooyman & Kiyak, 2008). Such care results in little or no financial detriment to the public. Caring for the terminally ill can be a painful experience, affecting not only the primary caregiver but also the entire family (Riley & Fenton, 2007). Unfortunately, the emotional and practical needs of the caregiver often go unrecognized and unattended. Cohen, Swanwick, O'Boyle, and Coakely (1997) state that primary family caregivers often experience strain or burden when they care for older relatives who are enduring declining health.

Riley and Fenton (2007) focused on the perspectives of nine primary caregivers that were attending to someone who was terminal ill in their qualitative study. The findings of this study established that many caregivers felt exhausted from the emotional impact of caring for someone who was terminally diagnosed. Some of the emotions and specific feelings described by the participants included fatigue, stress, distress, anxiety, depression, feelings of isolation, and suicidal thoughts.

Hooyman and Kiyak (2008) conclude that the negative consequences experienced by caregivers are conceptualized as primary and secondary stressors that are later manifested as objective or subjective burden.

Primary stressors, according to Hooyman and Kiyak (2008), are stressors that emerge from the care recipients due to their declining health. In contrast, secondary stressors according to the Family Caregiver Alliance (2006) arise when the actual caregiver begins to break down. Common methods of the deterioration include role strain, a deteriorating sense of mastery, and diminished self-esteem and competence over their caregiving role. Objective burden refers to the daily physical demands of caregiving that often create a disruption of "normal" family life (Hooyman & Kiyak, 2008). Fisher and Strandmark (2007) suggest that caregivers, while providing care to a spouse who was terminally ill, often ignored their own basic needs for sleep, rest, adequate nutrition, and social contact. This occurred because the needs of the ill spouse dictated the life of the caregiving spouse. Last, subjective burden refers to those feelings and emotions aroused in family caregivers such as grief, guilt, worry, loneliness, and sadness (Hooyman & Kiyak, 2008).

Additional stressors experienced by caregivers are linked to the financial costs of caregiving. Approximately 80 percent of caregivers regularly leave work early, and approximately 40 percent ultimately are forced to move from full-time to part-time jobs. This transitional step can often become a precursor to leaving the labor force entirely (National Alliance for Caregiving & AARP, 2004). A study by Grunfeld et al. (2004) supports this conclusion by establishing that the cost of necessary prescription drugs is among the most significant contributing factors to financial stress. As a corollary, caregivers and families who provided care for those without extended health insurance are most unfortunate in that they are forced to endure the entire financial burden of the illness (Grunfeld et al., 2004).

Gender Differences in Caregiving Experiences

The differing experiences of males and females as caregivers are an interesting facet of the overall issue, which must be taken into account. The Family Caregiver Alliance (2004) asserts that although gender roles have evolved with the gradual changes in society over time, to this day women continue to be the primary caregivers. It is believed that women perpetuate the caregiving field because they are socialized to be nurturing and caregivers (Hooyman & Kiyak, 2008).

Hooyman and Kiyak (2008) estimate that among primary and secondary caregivers, 36 percent are wives, 29 percent are daughters-in-law, and the other 20 percent consist of daughters, nieces, grand-daughters, and male relatives. Those men who do fulfill the role of caregivers are usually husbands, sons, and also son-in-laws. Male caregivers have a tendency to focus more on instrumental tasks such as house chores, yard work, and financial management (Sanders & McFarland, 2002). Kramer (2002) contends that generally speaking there is little emphasis placed upon male experiences as a caregiver. To put it plainly, studies on male caregivers are sparse. However, Kaye, Crittenden, and Charland (2008) has argued that practitioners must keep in mind that many older men believe that stigma is attached to seeking help, leaving them without the advantages of health care services that may help ameliorate their duties as caregivers.

The Family Caregiver Alliance (2006) suggests that the average caregiver is a 46-year-old-married female who works outside the home and earns an average yearly income of $35,000. Navaie-Waliser et al. (2002) indicate that physical problems affect 25 to 30% of caregivers. It is documented that these physical problems are most prevalent in middle-aged, unemployed African American caregivers. Furthermore, Mittelman (2002) indicates that a primary caregiver who is female is more likely to experience headaches, exhaustion, back pain, sleep disturbances, weight changes, elevated blood pressure, and a poorly functioning immune system often resulting in colds or the flu.

It is important to acknowledge and understand existing information regarding gender implications for caregiving because this study will conduct interviews with both male and female caregivers of individuals who were terminally ill.

Caregiver Grief in Terminal Illness and Bereavement

Although terminal illness conveys loss for both the ill and their caregivers, less attention is paid to the sense of loss experienced by the caregiver (Waldrop, 2007). Sanders and Saltz (2003) indicate that awareness that caregivers experience normal anticipatory grief while engaged in the caregiving process is mounting. Caregiver grief, according to Meuser and Marwit (2001), has been described as the intellectual, affective, and existential elements of changing care demands and expectations.

Waldrop (2007) defines that in order to conceptualize the different responses to illness, caregiving, and loss, it is necessary to distinguish between distress, bereavement, and mourning. Distress, according to Waldrop (2007), is defined as the unpleasant emotional experience of a psychological, social, and spiritual nature that may interfere with the capacity to cope well. Waldrop (2007) defines grief as the complex response to death and losses of all kinds, including emotional, psychological, social, and physical reactions. Bereavement, according to Waldrop (2007), is a state of having lost a significant person to death. As a corollary, mourning is the process of adapting to the loss and reforming the psychological ties with the person who died (Klass & Walter, 2001).

In order to fully understand the demands of caregiving and the intensity of the active dying process, it is imperative that the researcher acknowledge that the manner in which a family functions during the course of a terminal illness can influence the caregiver's health (Shultz & Beach, 1999). This dynamic can affect the health of the caregiver long after the care recipient has passed on.

Waldrop (2007) found that caregiver grief during the end stages of care constituted a state of heightened responsiveness. In this study it was concluded that grief was often manifested through anxiety, depression, fearfulness, restlessness, and an inability to concentrate. For many caregivers, the losses continue to emerge even after the care recipient dies and the caregiver is no longer carrying-out the role of a caregiver.

Included in the current study are comprehensive interviews with former caregivers who provided care to a terminally ill individual.

Theoretical Framework Guiding Conceptualization

The conceptual framework that is utilized for this study is based on role theory. Social psychologists contend that role theory is the process by which individuals are socialized into role behavior (Turner, 1996). The role adopted by the individual is believed to place stress on the individual, but nevertheless they still need to carryout this role.

Furthermore, role theory suggests that an individual's sense of self is influenced by the various positions he or she occupies and the effectiveness to which the individual is able to carryout their role (Turner, 1996). Role theory would suggest that the role of the caregiver is an achieved position. The term achieved position means that individuals enter such positions through achievement. This is the case of primary caregivers, who through their direct involvement in the care of the terminally ill achieve the position of caregiver.

It is important to point out that role theory includes a term known as role conflict. Role conflict refers to the difficulties experienced by those performing their roles. According to Turner (1996), role conflict occurs when a person experiences incompatible demands in the performance of his designated roles. This framework is important because existing literature has shown that caregivers do experience role conflict, often manifested in caregiver burnout.

Summary

The literature review discussed caregiver stress and demands and also examined gender differences in caregiving experiences. An in depth analysis was made concerning caregiver grief in response to terminal illness and bereavement. Last, the literature reviewed the guiding theory that is relevant to the experiences of those who dedicate at least a portion of their life to care for someone who is terminally ill.

CHAPTER THREE

METHODS

Introduction

In addition to an overview of the study design and sampling methodology, this chapter provides information on the instruments utilized to collect and process data. This section also addresses the procedures for collecting and analyzing data. The safeguards that are implemented to protect participants of the study are also addressed in this section.

Study Design

The present study is intended to build on previous research and knowledge regarding the experiences of caregivers who have cared for someone who is terminally ill. More specifically, this study explores how the personal values or beliefs of the primary caregiver are shaped and or changed after the experience of caring for someone who is terminally ill. This exploratory descriptive study will utilized a qualitative approach by conducting semi-structured interviews. This method was selected because it best enables caregivers to share sensitive information and it allowed caregivers to better explain their experiences in caregiving. The positive methodological implications of this study are that the caregivers are able to use their own words to explain their experiences in caregiving. However, one limitation of the study, which warrants recognition, is the reliability of the semi-structured interviews. The reliability of the information obtained is an unavoidable concern anytime self-reported information is elicited.

It is important to consider the possibility that participants of a study may provide inaccurate information because they feel pressured to give certain responses in a face-to-face interview due to feelings of shame or guilt. Others may not divulge information accurately because the timing of the interview may coincide with a stressful life event or situation. A final concern about the veracity of the information is that participants may not be forthcoming in their dialogue because of timing limitations implemented in the interviews.

Sampling

The participants involved in this study of caregivers included male and females, although they varied in age, however, all were required to be at least eighteen years old. The length of time that caregivers cared for the care recipient varied among participants. This study did not place restrictions on the length of time that the care was to be given to terminally ill individual in order to participate in the study. However, this study sought caregivers who exercised primary responsibility for the day-to-day care of the care recipient during the end stages of life.

The caregivers will be recruited based on criterion sampling, having been the primary caregivers to someone who was terminally ill within the past three years. This sample was chosen to expand data from caregivers that would help understand their unique experiences as caregivers and explore how their beliefs and values were changed as a result of this experience.

Data Collection and Instruments

It is also necessary to note the limitations of the interviews in this study. One such limitation is that the information gathered in these interviews is completely dependent on the participant's recollection of their experiences, and thus the reliability of this information can at times be questionable. To address these concerns the author allowed participants of the study to expand on any of the questions asked in the interview. In an effort to minimize the potential effects of this problem, the researcher made it a point to offer clarification to any question whenever necessary.

Data will be collected through face-to-face interviews with caregivers. The semi-structured interview (see Appendix A) contains questions relating to basic demographic information such as sex, age, ethnicity, marital status, work status, education level, and spiritual preference. Participants will be asked information about the care recipient, such as the terminal diagnosis, and the relationship between caregiver and care recipient. Participants will also be asked questions regarding the burden placed on the caregiver. The interview also included questions that help understand the nature of the relationship between the care recipient and caregiver. Those also assist in exploration of the caregiver's identity development as a result of the caregiving experiences. The interviewer will also ask strength based identity questions that facilitate understanding of what the caregivers have learned from their experience as a caregiver and also what they would like other caregivers to know.

Procedures

Data will be collected through face-to-face semi structured interviews with ex-caregivers. The interviews will be at the convenience of the caregiver and conducted in the caregivers' homes. The author will present the ex-caregiver with informed consent information (see Appendix B) prior to initiating the interview and explain to the ex-caregiver that the interview is expected to last between 40 minutes to one hour.

Protection of Human Subjects

To ensure the protection of participants of the study, informed consent letters will be provided and obtained from all subjects. Participants of the study will also be informed that participation in this study will be voluntary and confidential; the information shared by participants will not be disclosed to anyone at anytime. Participants will be informed that the information they share will not be associated will his/her name during anytime in the study. All tape recordings and notes were locked in a file cabinet and destroyed upon completion of the study. Furthermore, the participants were told through the informed consent letter that they are not required to answer any question, which they felt is distressing. After the interview is completed the participant will be provided with a debriefing statement (see Appendix C), which explained how the results of the study could be obtained. The debriefing statement also provided a contact number where the author's supervisor could be reached in the event any future questions regarding the study arose.

Data Analysis

Interviews will be audio recorded and then transcribed verbatim. Analysis of the data will begin with open coding and identification of meaning. A more in-depth analysis will take place when each line is examined for natural emergent and reoccurring themes.

The author of this study will utilize a journal to keep a written record of the methods of study being used and to record the identified meaning units of the data. The journal will also help keep a written record of the rules that will guide the definition of categories and the assignment of codes to the found categories.

Once the data have been coded into separate categories the research will identify the similarities and differences between the categories in an attempt to detect relationships among all of the existing data.

Summary

This section outlined the sample of the study, how the data were collected, the procedures involved in gathering the data, and analyzing it, and how the author protected the subjects that voluntarily participated in the study.

CHAPTER FOUR

RESULTS

Introduction

This chapter provides both descriptive and narrative accounts of the personal experiences that respective caregivers shared concerning the time they provided care to an individual stricken with a terminal illness. This chapter will present an analysis of the emerging themes found in the caregivers' experiences. In addition, this chapter will provide this researcher's interpretation of the narrative data, which describes the caregivers' experiences.

Presentation of the Findings

The sample was comprised of seven family caregivers who provided care to a loved one who was faced with a terminal illness. Four of the caregivers in this study were male and the remaining three were female. The age of participants ranged from 41 years to 78 years. The ethnic background of the sample included three Hispanics, two Caucasians, and two Japanese caregivers. The religious preference of the sample consisted of four Roman Catholics, one Christian, one Jew, and one atheist. The participants in the study provided care to individuals with varying diagnosis that included diabetes, cancer, Alzheimer's disease, and end stage liver failure.

In this sample, Participant Three and Seven provided care to a mother, Participant Two provided care to a father, and Participants One, Four, Five, and Six provided care to a spouse. The length of time participants provided care to a loved one ranged from 2 weeks to 14 years.

Interpretive analysis of the interview data provided by the caregivers revealed the themes that emerged with respect to the impacts and experiences of caregivers. These emergent themes included the (a) acquisition of knowledge and skills regarding medical procedures never done before, (b) self sacrifice to ensure the well-being of the care recipient, (c) caregivers serving as advocates, (d) satisfaction knowing they did the best they could, and (e) finding unexpected meeting places to join with or remember their loved one.

Theme 1: Acquisition of Knowledge and Skills Regarding Medical Procedures Never Done Before

Many caregivers reported being faced with the task of learning to perform medical procedures that needed to be done to ensure the physical well-being of their loved one. For example, Participant Five reported that he was forced to face his life long fear of needles when his wife required daily shots. The caregiver recalled overcoming this fear and being able to provide his wife with "daily shots in her stomach" (personal interview, January 2010). Participant Two reported having to be trained in the complex process of peritoneal dialysis. Of this procedure, she stated "peritoneal dialysis became a full-time job for me, not just during the day but also at night" (personal interview, January 2010).

Caregivers who did not receive formal training in the medical treatment of a loved one faced increased fears and anxiety. Participant Three recalled the anxieties of having to begin feeding his mother via a feeding tube in her stomach. He stated that feeding his mother "required round-the-clock care, because she would try to pull the feeding tube out" (personal interview, January 2010).

For some caregivers the simple task of administering medications also brought forth unforeseen challenges. For example Participant One explained how the pain medication she provided to her husband led him to have serious constipation problems. He went on to say, "This became a big battle all the time because I would assist him with taking the feces out" (personal interview, January 2010). Another caregiver, specifically Participant Four, struggled with the unforeseen challenge of deciding whether or not to provide his wife with medication that was part of an experimental drug trial. With respect to this difficult decision, Participant Four stated:

> The doctor, my wife, and I agreed to it. The experimental drug was $4,000 every two weeks and the health insurance refused to pay for it, but I was able to find someone who would be able to work out a deal through the pharmaceutical company where they would allow her to take it for free. (personal interview, January 2010)

The need for training and expansion of knowledge and skills regarding medical procedures varied according to the care recipient's medical needs. However, despite the differences and unforeseen challenges with which each caregiver was faced, each shared a common willingness to expand their knowledge and skills through educational training. In each instance this was done for the sole purpose of helping ensure the well-being of their loved one.

Theme 2: Self-Sacrifice to Ensure the Well-Being of the Care Recipient

When the caregivers where asked what they were most proud of in relation to their caregiving efforts, the emergent theme was that of self-sacrifice. All seven participants in this study suggested that at one point or another while providing care to a loved one, they felt it necessary to put their needs on hold to ensure the well-being of the care recipient.

Several caregivers in this study provided care to their loved one while they personally struggled with their own health. For example Participant Four shared,

> While she was sick, I had a herniated disk in my back and I had a very hard time walking, but I delayed surgery because I wanted to be with her. I was taking her to her radiation while I was walking with a cane and could barely walk at that time. (personal interview, January 2010)

The ways in which caregivers made sacrifices varied. Some caregivers were driven to make sacrifices related to their own individual health, and others made sacrifices and changes in regards to their lifestyle. For example Participant One stated "My diet also changed, I wasn't going to cook different for myself, and I mean it was sufficient enough for even myself" (personal interview, January 2010). She also stated "I stopped sewing because all I did was care for him. I stayed close to him all the time. I never left his side. It was important to me to stay close to him" (Participant One, personal interview, January 2010).

Two of the caregivers interviewed stated that they took time off from work to become the full-time caregivers of their loved one. An example of this was Participant Six who stated, "I took time off from work for a whole year. I asked for a family leave. I stayed with him and it was different" (personal interview, January 2010). Another example was Participant Four who said, "As soon as I learned she was sick, I stopped working. I wanted to be able to look back on that experience on my death bed and feel I did exactly the right thing for her" (personal interview, January 2010).

The degree to which caregivers had to modify their lifestyle and employment varied. For example, Participant Two stated,

> I couldn't keep leaving my house during the day because I could not leave him unattended; that is why I moved my office to my bedroom for the last year and a half. I worked from my bedroom and cared for him in my own home. It was very hard doing it all. (personal interview, January 2010)

Another example was Participant Three, who shared that the decision of providing care for his mother was his because his mother had already been sent to a nursing facility (personal interview, January 2010). However, Participant Three said that, "upon observing the care and amount of attention she received in the facility, I decided we would bring her home and I would be the one to give her care" (personal interview, January 2010).

The amount of time invested in the care of a loved one entailed daily adjustment and personal sacrifice for the caregivers. For example, many of the caregivers divulged having to function with only a few hours of sleep per night on a daily basis. Participant One estimated caring for her husband "11 or 12 hours per day" (personal interview, January 2010). Participant Two stated, "For the last two years of life it progressed to 24 hour care around the clock. It was exhausting and demanding. I did not sleep the whole night through but slept two or three hours at a time" (personal interview, January 2010).

Theme 3: Caregivers Serving as Advocates

The caregivers in this study experienced more than personal sacrifice. Being the primary caregiver meant that they had to serve as the personal health advocates of their loved one. This was particularly true when the health of the care recipient significantly declined.

An example of this was Participant One who said, "I asked the Lord to tell me when it was time, and I just felt it one day. We went to the Doctors office and I asked him Doctor [sic] please order hospice for us and he did" (personal interview, January 2010). Participant One also said, "I know he would be proud of the way I advocated for him medically. I was being his voice because he was always a quiet mannered man" (personal interview, January 2010).

Regarding advocacy efforts Participant Three suggested that, "It's important for caregivers to ask questions and do the thing that is right for them and what they believe is best for the patient; which may not always be the what the professionals believe" (personal interview, January 2010). Participant Four stated, "Reading on the subject helped me. I was familiar with every brain tumor trial going on in the world. I also switched doctors and went from a local doctor to the head of the neuro-oncology at UCLA" (personal interview, January 2010). Furthermore, regarding his advocacy efforts Participant Four went on to say, "The doctors have hundreds of patients, but my wife is my only client" (personal interview, January 2010).

For the caregivers who advocated for the interests of their loved ones, the act of advocating was a way of demonstrating their love, loyalty, and commitment to the care recipient. For instance Participant Two said, "My father was very thankful, he told me every day. He was proud of the way I protected him and defended his medical rights all the time" (personal interview, January 2010). The same participant also said, "My father had a lot of faith in me and he trusted me very much. He was confident going to the doctor because I was with him in every appointment" (Participant Two, personal interview, January 2010).

According to several participants, advocating and ensuring a loved one's well-being increased the level of emotional intimacy between the caregiver and care recipient. An example of this was Participant One who shared, "I felt more close to him. Towards the end he was not just my husband but more like my child" (personal interview, January 2010). This caregiver also stated that she was proud to know that no matter how hard it was to care for him in his last days, "I never gave up on him" (personal interview, January 2010). Advocating for a loved one was found to be a source of pride for many of the participants in this study. For example Participant Three stated "I took her out of the nursing home and cared for her at home at the risk of not knowing all the medical procedures" (personal interview, January 2010).

Theme 4: Satisfaction Knowing they did the Best they Could

Each caregiver was asked what they learned from being a caregiver and what they would advise another faced with the responsibility of caregiving. The resulting narratives soon revealed an emerging theme of personal satisfaction as the caregivers each knew they had done everything they possibly could for their loved one.

Participant Two stated,

> I learned that no matter how exhausted, tired, or time consuming it was for me to take care of my dad, the peace of mind I have is priceless. I cannot look back with regret because I know I did everything that I could to help him when he needed it; this has left me with no regrets. (personal interview, January 2010)

Participant Six shared, "I did everything for love. I do not see myself as a caregiver. I see myself as the wife who did everything I could for my husband; it was my responsibility and this brings me so much peace" (personal interview, January 2010). Similarly, Participant One said, "I'm fully satisfied that I did this for him; no regrets. Before I experienced this I didn't consider myself a caregiver but now I know that I can do it" (personal interview, January 2010).

Many caregivers suggested that looking back at their achievements as caregivers has helped them move on. After his experience caring for his wife Participant Four said,

> I think you want to be able to do the right thing. I want to be able to look back on my deathbed and feel that I did the right thing for the right reasons. I

> tried to share my pain with family and friends to get me stronger, and moving forward. (personal interview, January 2010).

Participants in this study also offered advice to other caregivers. For instance, Participant Five stated, "You have to do it! It is rewarding in a sense. Looking back, it kind of sounds selfish but it is rewarding. I did everything possible to the best of my ability" (personal interview, January 2010). Additionally, Participant Two suggested,

> If you have to provide care to someone, no matter who they are it is important to do it with love and compassion. Never make the person feel they are bothering you or that it is difficult or hard for you. If you do this, at the end you will feel peace of mind, have a clear conscious, and also be at peace with God. (personal interview, January 2010)

Theme 5: Finding Unexpected Meeting Places to Join with or Remember their Loved One

After the passing of a loved one, adjusting to a new way of life is a difficult process. This is particularly true for individuals who have provided care, time, and dedication to a dying loved one. In this study participants were asked to share what memories, feelings, emotions, or items they have held onto of their loved one.

Participant One shared,

> I have kept his favorite chair, I like to sit on it now. I keep his watch next to his picture and I also like to keep mints next to the sofa because he always liked to have those there. (personal interview, January 2010)

Participant One also indicated that she feels close to her husband while observing things around her. She indicated that these things might include,

> A beautiful sunset he would always comment on, or when the moon was just a sliver. So the view of the mountains, the sunset, and the moon are places that we meet. I wonder if he can see the moon from the other side, where I can only see one side of the moon. (personal interview, January 2010)

For other participants in this study a meeting point with their loved one is found in everyday things, such as food. Participant Two, who provided care for her father, recalls how important her father's diet was during the time she cared for him. As a result of this experience

Participant Two stated, "I appreciate my health a lot more. It changed the way I look at nutrition. There are certain healthy foods, or fruits like papaya that remind me of him when I see them" (personal interview, January 2010).

Another example was provided by Participant Four, who states that having videos and pictures and artwork of his wife have helped him heal and carry-on in life (personal interview, January 2010). Participant One said, "I have pictures of our life together. I have some paintings that I did of my wife, particularly one where she is seeing our first child, which still hangs in my house" (personal interview, January 2010).

This participant also suggested that the family he created with his wife before her passing is a meeting point with his beloved wife. With respect to this issue Participant Four said, "My children are my greatest gift and something we will always share together. I also speak to my wife's mother every single day" (personal interview, January 2010).

For some caregivers in this study the loss of their loved one has brought adjustments to ordinary things such as listening to music on the radio. For example, Participant Six said,

> I used to cry every time one of his favorite songs was played on the radio. He loved his music but now that time has passed by, I have learned to appreciate it and I feel him close to me when I listen to his music. (personal interview, January 2010)

Participant Six also shared, "I try to deal with the loneliness by doing more stuff, like scrapbooking. I enjoying finding old pictures and putting them together in the computer, arranging them and making them pretty, this makes me feel closer to him" (personal interview, January 2010). Additionally, two caregivers in this study shared that their loved one's favorite films have taken on further meanings in their lives, serving as a meeting point with their loved ones. Regarding films, Participant Five said, "I wanted to keep all her movies, especially the comedies, because I remember watching them with her all the time. I couldn't count all the times we watched them together. Having her VHS movies reminds me of her" (personal interview, January 2010).

Summary

This chapter examined and discussed the qualitative, narrative data found in this study. The qualitative data offered by former caregivers were gathered, analyzed, coded, and categorized into themes. The qualitative outcomes and limitations of this study are further interpreted and discussed in Chapter Five.

CHAPTER FIVE

DISCUSSION

Introduction

Chapter Five sets forth the conclusions that were reached after an analysis of the data from this qualitative study. This final chapter provides a summary discussion of the findings and limitations of this study. In addition, this chapter provides recommendations for social work practice, policy, and ways to improve the efficiency and quality of research in the field.

Discussion

The purpose of this study was to examine the experiences of caregivers who have provided care to someone faced with a terminal illness. The study utilized a qualitative approach as the data were gathered through personal interviews. There were a total of seven caregivers who participated in this study; four were male and the other three were female.

Some of the outcomes of this study were consistent with existing qualitative and quantitative research. This existing research has found that caregivers are often faced with the task of learning new information and building new skill sets related to medical procedures that they had never performed before.

One individual who provided care for his mother recalled his agreement to have a feeding tube surgically placed in his mother's stomach. Participant Three recollected, "I had to learn how to feed her via a tube and then we brought her home. It was a very scary time" (personal interview, January 2010). This insightful statement supports the research of Kalanins (2006), who contends that "family caregivers of the terminally ill need education and support; a major stressor for caregivers is uncertainty about their own knowledge and skills." Another caregiver who looked after her father stated, "I had to be trained to do peritoneal dialysis, not just during the day but also at night" (Participant Two, personal interview, January 2010). This experience is supported by prior research, which suggests "when the illness has a more progressive nature, caregivers acquire the necessary knowledge and skills over time as patient needs and the care requirements changed" (Kalnins, 2006).

The caregivers in this study all shared common experiences, which existing data suggests is also a normal occurrence. For example, Fisher and Strandmark

(2007) contend that while caring for a critically ill spouse at home, the surviving spouse tends to ignore his or her own basic needs for sleep, rest, and adequate nutrition. The narrative accounts of caregiving spouses in this study are consistent with this assessment. Participant Six stated, "I was only sleeping 2 hours a day. He used to wander around all night and I was afraid he would fall. So as soon as he would get up I would also wake up" (personal interview, January 2010). Another participant who cared for her husband shared a similar experience when she recounted how much her diet changed during the time she cared for him. A further example came from a husband who reported having to delay his back surgery because he wanted to be available for his terminally ill wife.

Interestingly, the findings of this study suggest that the caregivers interviewed discovered an overall satisfaction in having been the primary caregiver of their loved one. This satisfaction occurred despite the fact that caregivers were often expected to learn new medical skills, act as personal advocates, and often times elected to selflessly provide care at the cost of personal sacrifice.

This study is consistent with the research and findings of Koop and Strang (2003), who indicate that caregivers generally experience an overall positive reaction following their tenure as caregivers. Furthermore, they found that caregivers reported an overall sense of having accomplished something difficult and extremely valuable (Koop & Strang, 2003). An example of this was Participant Two who said, "I know I did everything that I could to help him when he needed it, and this has brought me no regrets and satisfaction" (personal interview, January 2010). Another example was provided by Participant One who stated, "I'm fully satisfied that I did this for him, no regrets" (personal interview, January 2010). Participant Six also shared, "When I married him, it was until the end, good or bad. I did everything that was in my power to help him and in a way this brings me satisfaction" (personal interview, January 2010).

Participant Three said, "I don't believe everyone is cut out for the work and demands of caregiving, but I am glad that I did it" (personal interview, January 2010). Lastly, Participant Five said, "I learned that I can take care of somebody. Looking back it kind of sounds selfish but it is rewarding. I have a sense of accomplishment. I did everything to the best of my ability" (personal interview, January 2010). These statements are consistent with the findings of Koop and Strang (2003), whom suggest that a caregiver's personal confidence and sense of self-efficacy are typically enhanced by his or her caregiving experiences.

Limitations

There are several potential limitations of this study. The first limitation worth noting is the limited sample size. Given that there were only seven participants in this study, the limited data collected cannot be assumed to be representative of the general population of either male or female caregivers.

A second limitation to this study is that the data gathered from the sample was self-reported. The participants provided viewpoints and perspectives regarding their respective experiences as caregivers through face-to-face interviews. This method does not eliminate the possibility that some participants may withhold, minimize, or exaggerate information they shared due to emotional discomfort related to disclosing personal experiences.

A third limitation to this study relates to the researcher's level of experience. Since the interviews were semi-structured, the way in which questions were asked or interpreted by this researcher or the participant might have varied. Additionally, the results of this study are not generalizable to the larger population because the sample was collected through snowball sampling. Despite the fact that this researcher obtained a geographically diverse sample, all participants in this study reported having felt satisfaction in providing care for their loved one. This is important to recognize because not all individuals faced with the responsibility of caring for a loved one may necessarily feel this same satisfaction, and these varying views are not represented in this study.

Recommendations for Social Work Practice, Policy and Research

The results of this study indicate that being the primary caregiver to someone who is faced with a terminal illness results in both negative and positive experiences for caregivers. For those individuals working in the field of social work, it is important to acknowledge the historical involvement of the social work profession in the hospice movement.

According to Parry (2001), the hospice movement that took place in the United States in the early 1970 was led by Zelda Foster, an American social worker. Through her involvement with the International Work Group on Death and Dying, Foster helped develop the standards for hospice care (Parry, 2001). Since the 1970's the profession of social work has been associated with issues relating to those who are terminally ill and those who provide care to improve the quality of their life. According to the NASW (2010) hospice social workers carry an average caseload of 24.2 patients, compared to a nurse's average of 13.3 patients. From these existing figures one can deduce that the involvement of the social work profession in the care and treatment of the terminally ill is very significant.

It is due to the significant involvement of hospice social workers that all social workers are encouraged to have a thorough training and understanding of the implications informal caregiving can bring to the primary caregiver. These implications may include an understanding and appreciation of the financial costs and physical demands the caregiver might face. Social workers must also acknowledge and address the mental health of the care recipient, who might experience an array of emotions, which may include guilt, anxiety, fear, anger, and isolation, among others (Hooyman & Kiyak, 2008).

The results of this study and the existing literature confirm that the social work practitioner should maintain an updated list of references and resources that can be provided to a caregiver. These resources may include information regarding home health aid service agencies, mutual aid groups, and other supporting organizations. Examples of such organizations might include the American Cancer Society or the Family Caregiver Alliance.

Social work practitioners should also provide caregivers with psycho-educational information and other resources that may facilitate their understanding of a particular illness. These resources may include informing the caregivers of current policies, such as the Family and Medical Leave Act of 1993, which allows up to 12 weeks of unpaid leave annually when an immediate family member with a serious health condition needs care.

In addition to these recommendations, it is suggested that the social work practitioner have an understanding of and/or experience in working with individuals and families. Much of the work carried out by hospice social workers is done in a families' home while the family members are present. According to Hooyman and Kiyak, (2008), social work practitioners should have an understanding of family dynamics in the home and assess if an intervention is necessary. For example, an intervention may be required when family members increase the caregiver's subjective (emotional) burden.

This study supports the need for further research regarding the specific differences between male and female caregivers. This recommendation is provided because the results of this study did not find significant differences in experiences among male and female participants. Currently there is more existing research detailing the experiences of female caregivers than there is for male caregivers. The conclusion reached in this study is that there are negative implications for caregivers throughout the caregiver's experiences. A continued lack of understanding or diagnosis of this issue may lead to seriously detrimental outcomes for the caregiver.

Conclusions

This study examined the impact of the caregiving experiences on the caregiver. The narrative accounts of the caregivers who participated in this study supported the findings reached in existing literature regarding end of life care. The majority of participants in this study suggested that being the primary caregiver of a loved one entailed personal sacrifice, but overall was a satisfying and life changing experience.

It is hoped that this study will help shed light on the experiences of informal caregivers who provide care to those faced with a terminal illness. It is this researcher's hope that this study will contribute to the knowledge and existing literature to help increase and develop understanding of the needs of caregivers. This is important because increased understanding of this matter may result in the creation of innovative interventions with caregivers and improvement in services already available to caregivers.

APPENDIX A

INTERVIEW QUESTIONS

Interview Questions

1. What is your gender?
2. How old are you?
3. What is your ethnic background?
4. What is your marital status?
5. What is your current work status?
6. What is your highest educational level?
7. What is your spiritual preference?
8. What was the diagnosis of care recipient?
9. What was your relationship to care recipient?
10. How long did you care for the care recipient?
11. Where was care normally provided?
12. On average how many hours a week was care provided for him/her?
13. What type of activities did you assist the care recipient with on a daily basis with?
14. How close where you to care recipient prior to becoming their personal caregiver?
15. How close did you feel to care recipient prior to death?
16. Did you have the opportunity to discuss death with the deceased before he/she died?
17. What difference has it made in your life to be a caregiver for him/her?
18. What have you held onto of the individual?
19. What are you most proud of about your caregiving?
20. What would he/she say of your care?
21. What would he/she be proud of about how you took care of them or your efforts?
22. Can you describe how you felt after the death of the care recipient?
23. How has your life changed since the death?
24. What have you learned from your experience as a caregiver?
25. What would you like to share or advice to another who was faced with the responsibility of caregiving?

APPENDIX B

INFORMED CONSENT

INFORMED CONSENT

The study in which you are being asked to participate is designed to investigate the caregiving experiences of ex-caregivers who provided care to someone who was terminally ill. The study is being conducted by Nayeli Corona, under the supervision of Dr. Rosemary McCaslin, Professor of Social Work, California State University, San Bernardino. This study has been approved by the Institutional Review Board, California State University, San Bernardino.

PURPOSE: The purpose of this study is to examine the experiences of primary caregivers who have provided care to someone who is terminally ill.

DESCRIPTION: In this study you will be interviewed asked to participate in a face-to-face interview and asked questions regarding your experiences as a caregiver and how these caregiving experiences have shaped your identity.

PARTICIPATION: Your participation in this study is entirely voluntary and you are free not to answer any questions at time and or withdraw from the study at anytime.

CONFIDENTIALITY <u>OR</u> ANONYMITY: Participation in this study is voluntary and confidential. The information shared by participants will not be disclosed to anyone at anytime. The information participants share will not be associated will his/her name during anytime in the study. All tape recordings and notes will be locked in a file cabinet and destroyed upon completion of the study.

DURATION: The expected duration of the interview is between 40 minutes to an hour to complete.

RISKS: There are no foreseeable risks associated with this study.

BENEFITS: A possible benefit of this study is that participants in this study may feel that the interviews are a therapeutic opportunity where they can discuss and process some of their personal experiences as caregivers. You may be eligible to enter the raffle of a gift certificate as a thank you for your participation.

VIDEO/AUDIO/PHOTOGRAPH: To ensure accuracy of data this research will include the use of audio recording.

I understand this research will be audio recorded Initials Yes ☐ or No ☐

CONTACT: If you experience any stress related to this study or have any questions or concerns about this study, please feel free to contact Dr. Rosemarry McCaslin, Professor of Social Work, at (909) 537-5707.

RESULTS: If you wish to obtain a copy of the results from this study the study results will be available upon completion in September 2010 at the Pfau Library at California State University, San Bernardino.

By placing a check mark below, I acknowledge that I have been informed of, and that I understand, the purpose and nature of the study, and I willing consent to participate. I also acknowledge that I am 18 years of age or older.

Please make a mark here: _______ Today's date:___________

APPENDIX C

DEBRIEFING STATEMENT

DEBRIEFING STATEMENT

The study you have participated in was designed specifically to explore the caregiver experiences of ex-caregivers who have provided care to someone who was terminally ill. It also sets out to explore how their experiences as caregiver's have shaped their personal identities.

Thank you for your participation and for not discussing the contents of the interview questions with other possible study participants. If you feel distressed in anyway after participating in this study please see the attached list of resources.

Your participation in this study will add to the research about social work knowledge regarding caregiver experiences. If you have any questions about this study, please feel free to contact Dr. Rosemarry McCaslin at (909) 537-5707. The study results will be available upon completion in September 2010 at the Pfau Library at California State University, San Bernardino.

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