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HOSPICE PATIENT'S PERCEPTION OF FAMILY SUPPORT

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HOSPICE PATIENTS' PERCEPTION OF FAMILY SUPPORT

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
Claudia Renteria

June 2014

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ABSTRACT

This qualitative and quantitative study focused on exploring hospice patient's perceptions of family support. Family support was conceptualized as which family member they expect to receive support from, types of support provided, frequency of support, family communication about medical illness, and type of support that is perceived to be most helpful. Fifteen participants between the ages of 70 to 98 were interviewed using purposive sampling. Findings showed that although participants found both physical and emotional support helpful, more than half reported perceiving emotional support as the most helpful. Recommendations for social work practice and research were discussed.

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DEDICATION

“I am because we are” is a quote I refer to when reflecting on my life’s achievements, as none would have been possible without the hard work and sacrifices of many. There a number of people without whom this thesis might not been written, and to whom I am profoundly grateful for.

To my parents to whom I owe all this to. Thank you for always reminding me of the great potential I carry within and for providing all the right elements to keep me pushing through my journey. There are no words that can express my appreciation for the unlimited amount of support you have given me and all of the sacrifices you have made to make this happen.

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CHAPTER ONE

INTRODUCTION

This chapter introduces the topic and focused problem. Additionally, it describes the purpose of the study. Finally, it explains its significance to the social work profession.

Problem Statement

In recent decades, there has been an increased interest in the field of death and dying. This has been beneficial not only for patients faced with end of life, but for their families, caregivers, health care providers, and social service providers, as it has offered knowledge on how to deal with issues that arise during this time. Since there is an increase in life expectancy in the United States and around the world, social workers are sure to face an increasing number of individuals dealing with terminal illness and other comorbidities. There are a significant number of older adults that are affected by some sort of chronic or terminal disease and according to Hooyman and Kiyak (2011), the risk of disease and impairment increases with age. Although the risk of disease and impairments increases with age, terminal illnesses are not necessarily associated with age.

Due to the increasing population, it is no surprise that interest on how to deliver medical care and services has increased. In the field of palliative care, there has been good research done on how to deliver better medical care and

support for patients and their families. More specifically, one sees a good amount of research done on how family and caregivers cope with physical and emotional demands when caring for a loved one in end of life. Yet, there continues to be limited research focused on how terminally ill patients cope when facing their mortality, their multiple losses, and the effects of these stressors on their mental health.

In order to assist individuals reach a good death, it is essential to research the perceptions of the individuals themselves, allowing them to share what works best for them, instead of the other way around. Terminally ill patients deal with much more than physical symptoms of a disease; they must learn to adjust to a new way of living, deal with reduction in mental and physical capacities, and develop healthy coping skills in hopes of still living a fulfilling life. Research shows that having family support is a good predictor of positive coping among caregivers, however, there is no research that looks into whether that is the case for the patients themselves. As social workers continue to be interested in how individuals achieve a “good death,” it is important to look at the impact family support has on terminally ill patients’ well being. It is also important to gain patients’ perspective on whether family support alleviates or contributes to already existing stressors.

Purpose of the Study

The purpose of this qualitative study was to assess family support as perceived by hospice patients. This study is different than others, as it focused

on obtaining this information directly from patients. Although there is much research done on end of life, there is limited research done on the types of support that promote healthy coping in hospice patients. Even less research is gathered directly from individuals faced with death. Most research studies focus on the caregivers of patients diagnosed with a terminal illness. Although this provides a good understanding of the field, it is vital to understand these concepts from the individuals' perspective. Lack of this research may be due to many factors, nevertheless, it is important to explore it since doing so can provide a greater insight of hospice patients' needs.

Being interested in the patient's journey to achieve a "good death," one should take into account all the factors that contribute to this state and the amount of impact they have. Palliative care agencies, such as hospice, were first developed in an attempt to address the needs of terminally ill patients. They have taken on the holistic approach to individual well being. They also understand that family contributes to this well being; as a result they also offer support to the families. Research done with hospice patients shows that family support plays an important role during this time. Research also shows that family support is rated to be one of the most important factors contributing to a "good death." Being aware that family support plays such a vital role during end of life, it is important to understand what type of family support is most helpful and beneficial as perceived by patients. Physical and emotional support are probably equally important considering all the physical and

psychological losses individuals face during this time. This is why it would be wise to assess who provides the support, the type of support they are receiving, the frequency of support, and family communication.

This research supports previous research in identify factors that contribute to a “good death.” It accomplished this by providing the field with hospice patients’ perspective of family support needs, and as a result can be used to assist patients works towards a “good death.” Knowledge of the impact that family support has on patients can also be used to further educate family and professionals in the field.

There is rich information that can be gathered directly from hospice patients that can further educate professionals in the field. Data was gathered through interviews to allow participants to express themselves in their own words. The interviews consisted of assesing family support. It also gathered demographic data that was be useful in finding corralations.

Significance of the Project for Social Work

As the aging population continues to grow, the social work profession, along with other diciplines, will be exposed to working directly or indirectly with this population. Palliative and end of life care is a growing area of practice, and social workers may feel unprepared to deal with the complex issues it encompasses (Csikai & Raymer 2003; Christ & Sormanti, 1999). According to National Association of Social Workers Standards for Palliative and End of Life Care (2004), “all social workers, regardless of practice settings, will inevitably

work with clients facing acute or long-term situations involving life-limiting illness, dying, death, grief, and bereavement” (<http://www.naswdc.org>). This study adds to already existing studies that focus on issues individuals face in end of life. It provides knowledge to social workers in the field and stresses the importance of family support in end of life in order to provide appropriate services to patients and their families.

The NASW Code of Ethics (2000) identifies the following as the core values of the profession: service, dignity and worth of persons, importance of human relationships, and competence. When providing services to a particular population, social workers must be competent. Social workers in end of life care should be knowledgeable enough to effectively practice. This study provides further knowledge about the field. It also acknowledges the worth and dignity of the person by taking in consideration the opinions of those facing end of life. It recognizes the importance of human relationships as it focuses on the impact of family support on terminally ill patients. This study provides information to further educate practitioners in the field, improving their competence.

The findings of this study are beneficial when applied to the generalist intervention process. In palliative and end of life care, practitioners already assess for family support. This study provides additional knowledge that would be helpful when conducting thorough assessments on available family support and the amount of family support provided. Practitioners will be better

informed about the support needs and as a result will be able to conduct more through assessments. In interventions and treatment planning, social workers will be able to incorporate this information in developing and implementing plans to strengthen patients' and families' ability to cope in end of life.

This study focused on addressing one question: How do hospice patients perceive family support?

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter explains the importance of this study. It reviews literature that is directly related to the impact of family support on hospice patients. It identifies gaps in the literature, methodological limitations, and conflicting findings. It also addresses the theoretical perspectives that have guided past research and those that will guide this study.

Theories Guiding Conceptualization

There are a few theorists that cover issues and crisis in late life that can be applied to death and dying. Erikson's developmental stage describes the crisis faced in this stage as Ego Integrity vs. Despair (Lesser & Pope, 2007). In this stage "people try to make sense of their prior experiences and to assure themselves that their lives have been meaningful, or they despair over their unachieved goal and ill-spent lives" (Lesser and Pope, p. 67). Hooyman and Kiyak (2011), also describe this stage as "establishing a sense of meaning in one's life rather than feeling despair or bitterness that life was wasted; to accept oneself and one's life without despair." In this stage an individual is faced with the crisis of accepting the inevitability of mortality and gains wisdom or experiences hopelessness and sadness for not being able to come to grips with death. If an individual is too worried and concerned with dealing with other

life stressors, such as the needs mentioned earlier, he or she may find it more difficult to focus on dealing with their death, which can lead to not achieving ego integrity. Family support greatly impacts an individual's ability to work through this crisis. Individuals faced with end of life have and are experiencing a great deal of loss, physically or socially. Elisabeth Kubler-Ross' five stages of grief provide a good view on what individuals may be dealing with during this time and how they are coping. She states that individuals that grieve go through five stages of grief with are: denial, anger, bargaining, depression, and acceptance.

Family Systems Theory is used to assess the dynamics within a family. Bowen conceptualizes family systems as an emotional unit, a network of interlocking relationships (Goldenberg, and Goldenburg, 2013). Like general systems theory, family systems theory states that within the system, there are regular interactions and that these systems are in one way or another interdependent. These interactions can be both a positive or negative support, impacting the individuals well being. Hospice patients often rely on family to provide support in the end stages of life. Consequently, family relationship greatly impact their wellbeing.

Similarly, social support theory focuses on the interactions between the provider and recipient. It looks at how these interactions are influenced by the nature of the relationship. It is important to consider family relationships and how they influence the support patients are receiving. According to Thoits

(1986), social support can be used to assist with coping in stressful situations, this is apparent in hospice patients.

A Good Death

There has been research that attempts to understand the concept of a “good death.” A good death can vary in definition depending on whose perspective it is. Granda-Cameron and Houldin (2012) state, “In sum, a good death is the result of a number of factors that can be grouped into patient factors, organization performance, and health care provider factors. These attributes included appropriate pain and symptom management, avoiding a prolonged dying process, attaining a sense of control, alleviating burden, and strengthening relationships with family and friends” (632). We see here that family and friend relationships, among other factors, contribute to what Granda-Cameron and Houldin refer to as a “good death.”

In addition, research done by Balein (2009), looks at factors associated with good death. Their findings, coming directly from patients, show that chances to resolve conflicts with family and friends and the presence of family members was rated an extremely important factor to a good death. This research shows the important role family support plays in end of life and in having a “good death.” Due to this, it was important to further explore what factors in family support promote or relieve stress in end of life.

Issues Faced in End of Life

There are several studies that research the perceived needs of individuals in end of life. Lokker, Zuylen, Veerbeek, Rijt, and Heide (2012), report that awareness turned out to be associated with acceptance of dying; patients who were aware of the imminence of death were more often at peace with dying and felt more often that life had been worth living than patients who were not aware. Communication and openness between physicians and patients about upcoming death is usually preferable and it gives the patient control over making decisions on the type of care they would like to receive in the end of life.

Furthermore, a qualitative study of the perception of people over the age of 80 on issues surrounding death and dying describes some of the common issues that arise when individuals are faced with death. Lloyd-Williams, Kennedy, Sixsmith, and Sixsmith (2007), stated that research shows that a good death involves addressing the individual's financial, spiritual, and emotional needs. Their research also shows that many individuals lived in fear of suffering and hoped for an easy and dignified death, with a particular emphasis with regard to burden through disability. Their finding also suggested that individuals would prefer a death that involved the minimum amount of physical or mental dependency and being able to stay in their home (Lloyd et al., 2007). They continue by stating that remaining at home was very important in their study and also shared that individuals aged

75 years and above are less likely to die at home than other adults (Lloyd et al., 2007).

Something that was found in several articles was the importance of patients having control in end-of-life decisions. Maintaining autonomy and control appear to be of considerable importance to terminally ill patients (Proot, Abu-Saad, Meulen, Goldsteen, Spreeuwenberg, & Widdershoven, 2004). In a study of patients with incurable cancer done by Kuuppelomaki and Lauri, 14% of patients mentioned lack of control as a source of suffering.

Family support directly impacts issues and needs in end of life. Therefore, it was important to consider what types of family support help hospice patients accept death.

Family Support in End of Life

The literature provides insight on the importance of family support for caregivers. A study done by Patterson and Dorfamn (2002), reports that “primary caregivers and the family members assisting those caregivers agreed that both instrumental support, such as physical care of the patient, and emotional support, such as phone calls and visits, were given to the primary caregiver” (321). This study showed the importance of family, as members depend on each other for support.

Although there is general information on the benefits of family support in end of life, there is little or no research that looks at the impacts on individuals’ overall well being. A study done by Wu (1990) on terminally ill

patients, found the effects of family support on one's mental health to be significant. The study reported "the group with immediate family support had a significant lower score in depression" (147). This supports the idea that family support does indeed impact the overall well being of individuals faced with death. It did not, however, identify what type of family support promotes one's well being.

Summary

This chapter focused on explaining the importance of this study. It provided a review of literature on end of life and the impact of family support on hospice patients. It identified literature gaps and suggestions for future research. It also provided theoretical frameworks in which this study is based on.

CHAPTER THREE

METHODS

Introduction

This chapter provides an overview on the purpose of the study. It describes the sample from which data was be obtained and how the data was be gathered. It also describes the intruments that were developed and were used for the study. This chapter touches on how confidentiality will be kept. Finally, it provides an overview on the procedures that were utilized to answer the research questions

Study Design

The objective of this study was to assess family support as percieved by hospice patients. This qualitative and quantatitive research explored what types of family support patients receive and what type of support they deemed most important. Open-ended questions were used as they allowed for participants to share their perceptions of the support they were receiving. Data was collected directly from patients, which is something that existing research is lacking. It provides greater insight of the impact family support has during this time in their lives.

The study came across limitations. There were some age groups, ethnicity groups, and gender groups that were represented more than others. Also, it only covered populations residing in Southern California.

This study focused in addressing one question: Does family support impact hospice patients' overall well being?

Sampling

Using purposive sampling approaches, a total of fifteen subjects were selected from hospice agencies. Subjects were deemed eligible for participation in the study if: 1. the patient had been admitted to hospice care services 2. the patient was between the ages 60 and 100, 3. the patient was alert and oriented to person, time, and place, and 4. the patient was able to communicate and make needs known. Subjects were excluded from the study if: 1. the patient was not deemed suitable by medical staff (e.g., because the subject suffered from dementia or at risk for severe psychological distress).

These criteria were developed for a couple of reasons. First of all, by selecting a sample from hospice agencies, it was assumed patient and family have come to some understanding and acceptance of the terminal illness. There were specific age groups targeted due to the difference with coping among different life stages. Because this study as interested in gathering the data directly from the patients, it was necessary that participants were able to communicate, make their needs known, and were alert and oriented to person, time, and place.

Data Collection and Instruments

The data gathered information about demographics and family support. The study utilized quantitative data analysis when collecting demographic data (Appendix A). Data consisted of information on age, gender, ethnicity, marital status, and if participants are eligible for Supplemental Security Income (SSI). A qualitative data analysis was utilized to assess for family support as questions were open ended (Appendix B). Family support was conceptualized as who offered support, types of support, frequency of support, family communication and type of support that was perceived to be most helpful. Research conducted by Patterson and Dorfman (2002), investigated family support for primary caregivers of hospice patients. They conceptualized family support similarly as it has been for this project. With these questions, they were able to obtain information directly from the caregivers on their perceptions on family support.

Procedures

This study utilized purposive sampling as it gathered data specifically from hospice patients. Researcher obtained potential referrals from staff. Potential participants were then be contacted through a phone call where they were given a brief explanation of the study. A visit was then made to patients that agreed to participate. Patients were provided with the informed consent followed by the interview questions. The researcher collected data by taking notes.

Protection of Human Subjects

Confidentiality was explained to participants via informed consent (Appendix D). Participants were studied by direct questioning, questions were read out loud by researcher. Data was gathered and stored in a flash drive. The flash drive remained in a lock box located at the reserachers home. Only the researcher had access to data collected. There was no personal identifying information gathered in this research.

Data Analysis

This project used a combined qualitative and quantitative approach. It assessed the impact family support has on hospice patients' well being. Quantitative data analysis was used when analyzing demographics. Nominal measurement was used to analyze gender, ethnicity, marital status, and SSI eligibility. Ratio measurement was used when analyzing the age of the participants.

Qualitative data analysis was used when analyzing family support. This approach was taken since these data was gather through the use of interviews. It allowed for participants to share their perceptions of the support they were receiving. Data was then categorized and coded to form patterns that led to interpretation of data.

Summary

This chapter provided an overview on the purpose of the study. It described the sample from which data was obtained and how it was gathered.

It also described the instruments that were developed and used. Finally, it provided an overview on the procedures that were utilized to answer the research questions.

CHAPTER FOUR

RESULTS

Introduction

This chapter will cover the demographics of the participants involved. These demographics consist of age, gender, ethnicity, marital status, and whether they were eligible to receive Supplemental Security Income (SSI). This chapter will also include a description of the qualitative data in regards to family support. Family support was conceptualized as who hospice patients expect to receive support from, the types of support offered by family members, the frequency of support, how the family communicates about patients' health condition, and the type of support hospice patients perceived to be most helpful.

Presentation of the Findings

Demographics

There were a total of fifteen participants in this study. The ages of the participants ranged from 70-98 and the mean age was 80.53. One participant was 70, two participants were 75, three participants were 76, two participants were 78, one participant was 79, one participant was 82, one participant was 84, one participant was 85, one participant was 87, one participant was 89, and another was 98. Findings reported that 53.3% ($n = 8$) of participants were female and 46.7% ($n = 7$) of participants were male. Caucasians made up the majority 80% ($n = 12$) of the participants, 13.3% ($n = 2$) were Hispanic or

Latino, and 6.7% ($n = 1$) were Native American. 20% ($n = 3$) of participants were married, 20% ($n = 3$) were divorced, and 60% ($n = 9$) were widowed. When participants were asked if they were eligible to receive Supplemental Security Income, 46.7% ($n = 7$) reported they were and 53.3% ($n = 8$) were not.

From which Relative do you Expect Support?

When asked what relative they expected support from, in the three homes where there was a living spouse, participants reported expecting most support from them. They further shared that although their spouse was the primary caretaker, the spouse greatly relied on additionally family support to meet all of their needs. In homes where the spouse was deceased, patients reported expecting most support from their children and other family members. Three participants shared expecting most support from their children, both sons and daughters. Three patients reported expecting most support from their son, but also from their daughter-in-laws and some of their close friends. Two participants reported expecting most support from their daughters only and three other shared expecting most support from their sons only. Another participant that had no immediate family shared expecting support from his niece and her husband. In homes where the spouse was deceased and the children lived far away, participants still relied on their children's visits and phone calls, but expected most physical support from their friends. Only one

participant reported relying only on a private caregiver, as they had no other type of support.

What Types of Support do Family Members Offer You?

When asked what type of support they received from family members, eleven participants reported receiving both, physical and emotional support, with an emphasis on physical support. When describing physical support, the most common responses were reported as assistance with instrumental activities of daily living (IADLs) and activities of daily living (ADLs). Some of the most common IADLs reported included food preparation, housekeeping, laundry, and transportation as some participants reported not being able to stand for long periods of time in order to accomplish these tasks. Other IADLs mentioned were management of medication and other health related needs, and assistance managing finances. As one participant shared, “I don’t even know what medication I’m supposed to take or when I’m supposed to take them, my wife takes care of that.” A couple of participants reported it very helpful since they were not able to keep up with their medications and could just no longer handle their financial responsibilities on their own. In addition to IADLs, participants reported receiving much support with ADLs. This included things such as bathing, oral care, grooming, feeding, and transferring. As one patient reported, “If it wasn’t for my sons, I wouldn’t be able to get up and use the bedside commode and would have to start using diapers.” Participants described emotional support as having family and friends to converse with in

person or via telephone, having them visit, and being able to participate in activities and events with them. As one participant shared when speaking about his wife, “even though I cant get up, we still do things together, like watch television or just talk.” Another participant shared “I still get to get out with my family, but only for a few hours because I get tired very quickly.”

Two participants reported receiving mostly emotional support only. This was seen in participants that had a higher level of independent and/or lived alone. Some of the most common descriptions of emotional support included having family visit or call them. They also reported receiving a sense of companionship and enjoying conversations when family members visited or called. Finally, the last two participants reported receiving mostly physical support, which included IADLs and ADLs, such as housekeeping, transportation, and hygienic needs. It is good to note that both participants that reported receiving only physical support were men.

How Frequently do Family Members Offer Support?

When asked how frequent they received support from family members, all participants, but one, reported receiving daily support. Some of them reported that this was done with additional support from other family members. Those who relied mostly on their spouse for support commonly reported this. As one of them shared, “My wife is the one that takes care of me, but my children help her with paying the bills or keeping up with the house chores.” Only one participant reported receiving support one to two times weekly. For

her this meant not receiving physical contact, but still received daily phone calls from her children.

How does The Family Communicate about their Medical Condition?

Participants were asked, “How do you and your family communicate about your medical condition?” Twelve out of the fifteen of them reported having regular communication about their medical condition and needs. Most of them stated that family communication about disease process was usually “open,” “supportive,” and “frequent.” As one shared, “I’m receiving hospice services so my family already knows what is going on.” Another shared, “my wife and I have also communicated very well. We have discussed my wishes in regards to my medical care and end of life, I trust that she will make the decisions that are best for me.” Another participant shared that he had discussed his wishes with his family in the past, but longer talked about the matter. Only two participants reported that they did not communicate with family about their condition at all. As one stated, “I just don’t like talking about it.”

What Types of Support do you Perceive as Being Most Helpful?

When asked what type of support they perceived most helpful, ten out of fifteen participants reported perceiving emotional support as most helpful, while the other five reported physical support as most helpful. There were common responses among those perceiving emotional support as most helpful. One of the most common was spending time with the family in

general. This was described as just being around family members, having family gatherings and events, enjoying the presence of their children, and engaging in family activities despite their limitations. One patient reported, “I like having my family over, it makes me happy to see everyone here.” Another patient reported enjoying having the children over, as they were able to do things together, like color on a coloring book. Some participants also shared relying on their family members for spiritual support, as they held “strong religious beliefs” and it helped them cope with their situation. One participant reported that daily encouragement was very helpful. When describing his wife, he shared, “she keeps me going and keeps me on track when I don’t want to push anymore.” In addition to family support, participants also shared that being able to engage in social activities with friends encouraged them to get up and going. One participant shared, “we go out in the morning to have coffee with old friends. Sometimes when I don’t want to go, my wife will push me to go and once I’m there I feel better.” This leads to the next common response of “companionship.” Majority of participants reported that having someone to talk was very important to them. As one participant shared, “My wife and I talk about everything, it really helps me get through things.” Another participant shared enjoying “being able to reminisce about the past” with her children and shared it helped her remember what a great life she lived. Others reported that a simple phone call a day to check in or watch television with them was enough support.

The remaining five participants who perceived physical support as most helpful also shared some common responses. These responses fell under ADLs and IADLs needs. It was common for those who were bedbound or had very limited mobility, to report ADLs support as most helpful. This included assistance with feeding and keeping up with their hygiene, such as bathing and oral care. All of the five participants reported perceiving assistance with IADLs as very helpful. This included assistance in making medical decisions and providing medical care, such as managing medication and visiting or checking in with them often. Additionally, they shared assistance with managing finances and taking care of household responsibilities helpful.

Summary

This chapter described the demographics of the participants involved. These demographics consisted of age, gender, ethnicity, marital status, and whether they were eligible to receive Supplemental Security Income (SSI). The chapter also included a description of the qualitative data in regards to family support. Family support was conceptualized as who offers support, types of support, frequency of support, family communication about health condition, and type of support that is perceived to be most helpful by hospice patients.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter will provide a brief summary of the findings collected directly from hospice patients. These findings include a description of the qualitative data in regards to family support. Family support was assessed as which relatives hospice patients expect support from, the types of support family members offer, the frequency of support offered, how the family communicates about the patient's health condition, and the type of support hospice patients perceived to be most helpful. This section will describe some of the limitations of this research. Additionally, this section will share recommendations for social work practice and research.

Discussion

This primarily qualitative study focused on hospice patients' perception of family support. The findings revealed varied response for each question. Within each question there were common themes identified.

When looking at what family members participants expected most support from, responses varied according to the available support hospice patients had. In the homes where there was a living spouse, all participants reported expecting most support from them. More than half of the participants, who did not have a spouse at home, reported strongly expecting support from

their children. There were no significant differences between sons and daughters. Only participants that had no immediate family reported expecting support from friend or caregivers. These findings show that when available, hospice patients expect all or most support from their family, having the spouse as their first choice. These findings also suggest that support is not gender based but rather is based on the complete family system. The findings are also consistent with social support theory.

When looking at the types of support received, most participants identified receiving a combination of physical and emotional support. It's interesting to note that the two who reported only receiving emotional support were female. Furthermore, the two who reported only receiving only physical support were male. These findings imply that females are more likely, than males, to reach out for emotional support, which can be directly influenced by culture and gender expectations. This is described in a study Hoyt (2009) conducted with males diagnosed with cancer. She found that "gender role conflict likely shape coping responses and may negatively affect the efficacy of men's emotion-directed coping efforts and adjustment to cancer" (p. 983). Additionally, she shared that "similar to coping processes examined in women with cancer, expressing emotions as a means of coping with cancer appears to be helpful for men" (p. 991).

It was expected that participants received daily or close to daily support from family, considering they were under hospice care and required higher

levels of care. Most participants reported receiving daily support. Only two reported receiving support on a weekly basis. It is important to note that these participants were more independent and mobile. They required less care and appeared to enjoy having the independence. All, but three families reported open communication about their health condition. There were no significant differences among these responses.

Much interest was placed on participants' perception of the most helpful support. Findings showed more than half of the participants perceived emotional support as the most helpful. Participants described emotional support as spending time with family in general. These findings are consistent with the concept of a "good death" as described by Balein (2009). Based on research done with hospice patients, Balein reported five common factors that patients associated with a "good death," of which all are somehow related to family support. These are listed in order of importance as, "coming to peace with God, praying, chance to resolve conflicts with family and friends, presence of family members and chance to say goodbye to important people in one's life." Additionally, these findings are also consistent with Erikson's developmental stage of Ego Integrity vs. Despair. Hospice patients heavily rely on family members to assist them in reflecting on and establishing a sense of meaning in their lives.

Overall, these findings showed that participants strongly expected and relied on family to provide support. Additionally, it showed that although both

physical and emotional supports are helpful, emotional support was perceived to be the most important to them.

Limitations

This study came across a few limitations. First of all, this was a small sample of participants. Therefore, generalization of the results to patients in similar settings requires additional research. Furthermore, more studies with larger samples are also needed.

Second, findings were from one hospice in Inland Empire/Southern California area. As a result, it is important that future studies be done in hospices in other areas of the country. The study consisted of predominantly Caucasian participants. Further research should include hospice patients from more diverse racial and ethnic populations.

Recommendations for Social Work Practice, Policy and Research

This study has implications for social workers, educators, and researchers. First of all, this study provides specific examples of the needs of hospice patients. This information can be used as a guide when assessing for family support and when choosing what interventions to implement. It emphasizes the importance of family support and the need to involve them to promote and facilitate a good death. Additionally, this study highlighted the idea of hospice patients reaching a good death with the support of family

members. Further research into what leads to a good death for hospice patients is vital in end-of-life care.

Conclusions

This chapter provided a summary of the findings collected directly from hospice patients. These findings include a description of the qualitative data in regards to family support. This section described some of the limitation this research came across. Additionally, this section shared recommendations for social work practice and research.

APPENDIX A
DEMOGRAPHIC QUESTIONNAIRE

DEMOGRAPHIC QUESTIONNAIRE

1. Age
2. Gender
 - a. Female
 - b. Male
3. Ethnicity
 - a. Caucasian
 - b. Black or African-American
 - c. Asian
 - d. Hispanic or Latino
 - e. Native America
 - f. Other
4. Marital status
 - a. Single
 - b. Married
 - c. Divorced
 - d. Separated
 - e. Widowed
5. Are you eligible to receive Supplemental Security Income?
 - a. Yes
 - b. No

APPENDIX B
FAMILY SUPPORT INTERVIEW QUESTIONS

FAMILY SUPPORT INTERVIEW QUESTIONS

1. From which relatives do patients expect support?
2. What types of support do family members offer the patient?
3. How frequently do family members offer support to the patient?
4. How does the family communicate about the medical illness?
5. What types of support do you perceive as being most helpful?

APPENDIX C
INFORMED CONSENT

Informed Consent

We would like to ask for your participation in a study that is interested in looking at some of the needs of individuals receiving hospice care. This study is being conducted by Claudia Renteria under supervision of Rosemary McCaslin, Professor of Social Work at California State University, San Bernardino. This study has been approved by the School of Social Work Sub-Committee of the Institutional Review Board, California State University, San Bernardino.

The purpose of the research project is to gain hospice patients' insight on family support. We are interested in further understanding what type of support promotes healthier coping among hospice patients.

Please know that your confidentiality is very important to us. All of the information you provide will remain confidential, this means we will not provide this information to any agency and information collected will only be used for the purposes of this research project. Your identity will be kept private, as you will not be asked to provide your name. You will only be asked to mark an "X" for agreeing to participate.

In participating in the following survey we ask that you answer the questions as honestly as possible. Participation is voluntary; refusal to participate or stop interview at any time will involve no penalty.

If you agree to participate, please finish reading this consent and sign with only an "X". Next, you will be asked to participate in an interview where a variety of questions will be asked. These questions will gather information about your demographics, family support, and mental health status. Questions will be read to participants. After both the consent form and the interview are done, the process will be completed. The interview will be audio recorded with your consent, but you may refuse to do so. Reading the consent form and completing the interview will vary in time, but should not take any more than 60 minutes.

There are no predictable risks associated with participating in this study. Answering some questions might create some discomfort. If at any time you feel uncomfortable, you are completely free to refuse to answer any question.

It is unlikely that you will directly benefit by participating in this study. However, the knowledge gained from this study may contribute to further understanding on some of hospice patients' needs.

For any questions regarding this study or participants' rights please feel free to contact Professor Rosemary McCaslin at (909) 537-5507.

If you would like to obtain a copy of the results of this study, please contact our library at 909-537-5091 or your hospice agency after September 2014.

I have read the information above and agree to participate in your study.

Signature: (Please just mark an "X", DO NOT put your name)

Mark: _____

Date: _____

APPENDIX D
DEBRIEFING STATEMENT

Debriefing Statement

I, Claudia Renteria, would like to thank you for your participation on this research project. The purpose of this research project is to gain hospice patients' insight on family support.

If you have any questions about the study, please feel free to contact Professor Rosemary McCaslin at (909) 537-5507. If you would like to obtain a copy of the group results of this study, please contact the library of California University of San Bernardino 909-537-5091 or your hospice agency after September 2014.

APPENDIX E
AGENCY APPROVAL LETTER

To whom it may concern:

I am a current student at California State University, San Bernardino who is conducting a study on the needs of individuals receiving hospice care. This study is under supervision of Rosemary McCaslin, professor of Social Work at California State University, San Bernardino and has been approved by the School of Social Work Sub-Committee of the Institutional Review Board, California State University, San Bernardino.

This letter is to confirm that you have approved this study to take place at your agency. Please keep in mind that confidentiality and anonymity is important to us and will be maintained throughout the study.

Agency Name: _____

Signature of representative: _____

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