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Elderly Cancer Patients' Use of Hope and Faith-Based Services: Social Workers' Perspectives

by

Kati Lynn Thayer, B. A.

MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catherine University and University of St. Thomas
St. Paul, Minnesota
in Partial fulfillment of the Requirements for the Degree of
Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/ University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of study. This project is neither a Master's thesis nor a dissertation.

Abstract

Due to the lack of research examining elderly cancer patients' utilization of hope and faith-based services in healing, the current study explored this idea as viewed from the perspective of social workers ($n = 7$) that worked (past or present) with elderly patients in medical settings or with adult cancer patients. Participants spoke to their experiences with cancer patients of all ages and in all stages of illness, not only elderly individuals with terminal cancer. This study found that both hope and faith-based services are an important component of the healing process for cancer patients of any age. The findings of this study indicate the need for social workers to recognize and foster hope amongst cancer patients of any age, and formally assess a cancer patient's hope throughout their medical journey, specifically in terms of what it is they are hoping for.

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Elderly Cancer Patients' Use of Hope and Faith-Based Services: Social Workers' Perspectives

The purpose of this research study was to explore how hospital or medical social workers view the utilization of hope and faith-based services in the healing process of elderly individuals with terminal cancer. Through the experience of a relative with cancer, the researcher noted that having hope and faith-based services to rely on can foster positive thinking which could lead to healing, whether physically or psychologically. The information provided in this introduction outlines relevant statistics related to the prevalence of cancer, introduces terms important to understand in relation to cancer and treatment options, a discussion of what the term elderly means, and descriptions of the variety of services and supports available to cancer patients from online supports to spiritual supports.

As elderly populations grow, emotional support to geriatric cancer patients will become increasingly important. Reports suggest that by 2030, “70% of all cancers will be diagnosed in the elderly” (News-medical.net, 2012). By 2050, geriatric populations are projected to reach 70 million (Ershler, 2003).

For the purposes of this study it is important to define exactly what cancer is. According to the American Cancer Society (2012), cancer is the growth and spread of abnormal cells in the body, and can have an external cause from something like cigarette smoke, or internal causes from things such as hormones or inherited mutations. There are some terms important to understand in relation to the course of cancer, including the use of the term terminal, as well as the different staging of cancers. The word *terminal* in relation to cancer is “generally understood to mean that the cancer can no longer be

treated or cured, and the patient is dying” (American Cancer Society, 2012). The National Cancer Institute at the National Institutes of Health describes the various stages of cancer, including those other than terminal. For example, *stage 0* indicates a cancer that is confined and has not spread; *stages I, II, and III* indicate that the cancer spread from the original site to other tissues such as lymph nodes, and a higher number signifies a wider spread. Lastly, *stage IV* indicates that the cancer “has spread to another organ(s)” (National Cancer Institute, 2012). Not only is the staging of cancer important to understand, but awareness of the prevalence of the disease is also important.

Cancer is an extremely prevalent disease; not only among the elderly. In the year 2012, there were projected to be 1,638,910 cases of cancer diagnosed (American Cancer Society, 2012). There are, however, some forms of cancer that are more common among elderly populations. For example, the most common forms of cancer in elderly men affect the prostate, lung, and colon, and these make up about half of the cancers diagnosed in this population (Hansen, 1998). Breast, colon, lung, and stomach are the most common cancers among elderly women, and also make up about half of the cancer diagnosed among this population (Hansen, 1998). It is expected that the elderly will contribute, in large part, to the growing number of cancer cases, which is projected to be 2.6 million by the year 2050 (Ershler, 2003). Overall, “all cancers combined (except non-melanoma skin cancer) were. . . almost 7-fold more frequent among elderly men. . . and around 4-fold more frequent among elderly women” when compared to a younger population (Hansen, 1998, p. 467). These statistics do a great deal to show what cancer looks like among the elderly.

Cancer can be treated in many ways, including approaches such as surgery, chemotherapy, and targeted interventions (American Cancer Society, 2012). For example, *surgery* is a treatment option and “can be used to diagnose, treat, or even help prevent cancer” and “it often offers the greatest chance for cure” (American Cancer Society, 2012). *Chemotherapy* is defined by The American Cancer Society (2012) as the use of medicine and drugs that travel throughout the entire body and allows for cancer cells, that have spread throughout the body, to be destroyed. *Radiation*, another form of treatment described by the American Cancer Society (2012), is one of the most common treatments, and is defined as using “high-energy particles or waves to destroy or damage cancer cells.” Other treatment options include: *targeted therapy*, or the use of drugs that attack only cancer cells while doing less damage to other cells (American Cancer Society, 2012); *immunotherapy*, which involves either stimulating one’s own immune system to fight cancer cells, or enhancing one’s immune system with man-made proteins (American Cancer Society, 2012); and *hyperthermia*, or raising one’s body temperature to a degree where cancer cells will be more affected by other treatments like radiation or chemotherapy (American Cancer Society, 2012). Not only are there many dimensions of cancer and its treatment, but there are also many things to consider when attempting to define the term *elderly*.

Currently, what defines *elderly* needs re-examination as people are living to be older and older, with the average life span of men and women now being 10 and 12 years longer than 45 years ago, respectively (Globalaging.org, 2012). Ershler (2003) stated that the age division between the young and the elderly was originally put in place when Medicare used the age of 65 as its age criteria for an individual to be able to access

benefits. Now that it is known that people are living longer, it is important to look at how the term *elderly* is defined, as well as looking at how to support them if they develop cancer in later life.

A variety of supportive services are available for those suffering from cancer. Historically, cancer among terminally ill patients has been addressed through supportive services such as palliative and hospice care. *Hospice care* is one form of supportive care provided to cancer patients, and involves “humane and compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible” (American Cancer Society, 2012). Hospice care can be provided in a variety of places such as residential settings, or in a patient’s home. Hospice also involves *palliative care*, or ways of managing the symptoms one is suffering from as a result of their disease, but it is not intended to cure the disease (American Cancer Society, 2012). According to the Agency for Healthcare Research and Quality and the U.S. Department of Health and Human Services, “most hospice patients in nursing homes were female, white, and aged 85 and older” (2012). This alone proves that the elderly make up most of the clientele receiving hospice services, especially in the nursing home setting.

A variety of other supports and services are available to cancer patients of all ages throughout the various stages of their illness. The American Cancer Society provides a variety of resources, such as an online support group for patients and families to connect with others who are in a similar situation. Also provided is the opportunity to keep a Personal Health Record to keep track of information and allow family and friends to see where a patient is in their journey (American Cancer Society, 2012). Aside from online services, in person support groups are also offered where individuals can share stories

and receive information. Transportation services to get to medical appointments can be arranged by simply entering one's zip code to find a volunteer driver. Educational classes are also offered, both online and in person, by entering one's zip code to find a location (American Cancer Society, 2012).

Aside from the variety of support services, spirituality has also been shown to have a positive impact on cancer patients. Hutchison summarizes the positive impact of spirituality when she states, "for both mental and physical health problems, religion and spirituality have been noted as major means of coping" (2011, p. 200). Specific faith-based services are available to cancer patients and their families, and may vary from one setting to another. Services could include prayer, counseling, worship services, coordination and communication with a faith community in a patient's hometown, classes focused on "healing, faith and life," as well as support regarding "end of life issues and decisions" (Cancer Treatment Centers of America, 2012). All of the above mentioned supports and services could bolster one's internal drive and motivation to endure, push on, and continue with the cancer treatment process.

Because the elderly population is projected to significantly contribute to the number of cancer diagnoses, it is important to look at how they go through the healing process. Strong evidence indicates that hope needs to be studied further, and specifically, hope in relation to the elderly with a terminal cancer diagnosis. Elliott and Olver (2006) state, "many have concluded that hope research is fragmented, imprecise, and episodic" (p. 138). Esbensen and Thomsen (2011) add, "there is a lack of knowledge about elderly people with cancer, especially in relation to those in the advanced stages" (p. 27). Based on the need for further research, the purpose of this qualitative study will be to examine

how hospital social workers view the utilization of hope and faith-based services, if at all, to help in the healing process of elderly individuals with terminal cancer.

Literature Review

The review of the literature explored some aspects of the history of the study of hope, the impact of social support, and the roles of both hope and faith-based services in the lives of individuals with terminal cancer.

History of Hope

The history of the scientific study of hope shows that different themes have evolved throughout the years. For example, in the 1970's and early 1980's, hope was viewed as being interpersonal as well as focused on the future (Butt, 2011). Then in the late 1980's and early 1990's, viewpoints shifted and hope was not viewed as time oriented, but rather, was more defined as being able to control "behavior or emotional responses" (Butt, 2011, p. E341). For example, Miller (1985) highlights this point by stating, "I believe that hope influences the healing response and is necessary to prevent the physical and mental deterioration that come with despair brought on by illness" (p. 23). This previous research on hope was not specifically conducted with terminal cancer patients, but with those newly diagnosed so very different themes may emerge when studied with terminal cancer patients.

Online Social Support among Cancer Patients

The Internet has been shown to be a great source of hope for cancer patients. The Internet is not only a source of illness-related information for them, but it also provides encouragement through different perspectives, such as story telling, and support groups (Dickerson, Boehmke, Ogle & Brown, 2006). In a study conducted by Dickerson, Boehmke, Ogle, and Brown (2006), 20 female cancer patients with an average age of 53 years, in a variety of stages of illness, were interviewed and asked how the Internet was a

resource for them in terms of their care. The authors found five themes in their interviews, and one of them that spoke to the benefits of using the Internet was that people were “Seeking hope with the newest treatment options while coping with fear in manageable ‘bytes’” (p. E11). The interviewees reported that the Internet was more up-to-date in terms of treatment options and that books were usually dated and told them, “there was no hope” (Dickerson et al., 2006, p. E11). Aside from reading negative information, patients were told by their doctors that nothing else could be done for them regarding their illness, so they turned to the Internet and found more hopeful information. It was also found that “sometimes information from the Internet provided peace of mind and hope” (Dickerson et al., 2006, p. E12). This study looking at online supports did not focus specifically on those in the terminal phase of their illness, but more broadly on any phase of illness. They also did not focus on the elderly, which shows reason to investigate the use of online supports within this specific population. Not only are the sources of hope important in relation to cancer patients, but it is also important to examine the impact having hope can have on a person.

Hope among Cancer Patients

The various benefits of having hope were found in an article by Mattioli, Repinski, and Chappy (2008), which stated that “Hope has been found to help patients adapt to and provide meaning in illness, maintain a high level of well-being, and give direction and a reason for being. It is also important in coping with various phases of illness” (p. 822). To further support this, McClement and Chochinov (2008) stated, “The findings of many studies demonstrate that living with hope is a significant factor that assists individuals to adjust to their cancer illness, reduce their psychological distress and

enhance their psychosocial well-being and quality of life” (p. 1170). The purpose of the study conducted by Mattioli et al. (2008) was to explore the role of both hope and social supports with cancer patients who were in the treatment phase of their illness. In this study, 14 patients, ages 51-79, from an ambulatory care unit, provided information regarding social support and hope in relation to their treatment. Mattioli et al. (2008) noted a positive relationship between both coping style and its effectiveness when used by cancer patients.

Mattioli et al. (2008) found four themes regarding coping mechanisms in the data from their study. One was the idea of “focusing on the bigger picture,” or not focusing specifically on the cancer and/or realizing that cancer did not have to control the patients’ lives, and was “not the center of my universe anymore” (Mattioli et al., 2006, p. 826). The second theme was “taking cover in the storm,” or avoiding the negative thoughts and/or fears that go along with cancer. Participants quantified this theme with statements like, “I don’t like to think about it. I try to avoid anything that reminds me of cancer” (Mattioli et al., 2006, p. 826). The third theme was “keeping it normal” or carrying on with life as the participants did before their diagnoses and/or starting treatment (Mattioli et al., 2006, p. 826). And the last theme was “reaching out/not in this alone,” that is using faith, prayer, and social support to gain strength. This study demonstrated that “Reaching out was a mechanism used to foster hope” (Mattioli et al., 2006, p. 826). This study illustrates the positive effects of a cancer patient having hope, but it does not focus specifically on the elderly.

Hope is also referenced by Elliott and Olver (2007) in the sense that it is a reason for receiving or continuing with treatment. Elliott and Olver (2007) conducted a study

with 28 patients with an average age of 61, who were all patients at an oncology clinic. All of the participants had stage four cancers and were “likely to die within 3 months” (p. 139). Qualitative interviews were the research method, and they were intended to get a discussion started on end of life. An example of a specific prompter was “Can you tell me about hope and hoping?” (p. 139). When the authors examined the information they gathered from their interviews, it was noticeable that the word hope came up a lot, often without any prompting on the topic. Elliott and Olver (2007) broke down their findings regarding hope into two categories: hope as a noun and hope as a verb. Hope was referred to as a noun in the sense that it is something one possesses, or a quality they have. Hope was also referred to as “a vital resource in [his] ‘fight’” (p. 142), and it was later stated that “even small amounts of hope. . . are deemed to play a significant role in the patient’s fight against their disease” (Elliott & Olver, 2007, p. 143). On the other hand, hope as a verb was said to imply doing something or hoping for a desirable future, which was the most dominant way in which hope was used as a verb.

Elliott and Olver (2007) stressed that “hope-as-a-verb appears to allow for acknowledgement that both the positive and the negative are possible in the future,” but if one has hope, they have the option or ability to consider the possibility of better, more desirable outcome even if it comes down to what kind of death they have (p. 145). Lastly, it was pointed out that those who have hope should be “actively engaged in their life,” especially in the terminal phase of illness (p. 145). This study more closely examines the impact that the possession of hope can have on cancer patients, and while the participants were older in age on average, there still was no specific focus on the elderly population. This again is more proof for the need to examine this issue in relation to the elderly.

Measuring Hope

Knowing how to measure one's level of hope is an important step to understanding its impact on an individual. Although standardized measures exist that assess levels of hope among terminally ill cancer patients, only the Herth Hope Index is normed for measuring hope among terminally ill, elderly cancer patients (Herth, K., 1992). This index contains a 12-question Likert scale assessment, with answers ranging from one to four, with a one signifying strongly disagreeing and a four signifying strongly agreeing with the statement (McClement & Chochinov, 2008). A higher overall score on the Herth Hope Index implies that the individual has a higher level of hope (McClement & Chochinov, 2008).

Another assessment, called the Nowotny's Hope Scale, was used by Esbensen and Thomsen (2011), when they did a follow up study with elderly individuals who received a new diagnosis of cancer. All of the 101 study participants met the criteria of a specific cancer diagnosis, or were undergoing treatment, or "receiving supportive hospital care for their cancer" (Esbensen & Thomsen, 2011, p. 27). The average age of the respondent in this study was 75 years old, and they were mainly female respondents. The Nowotny's Hope Scale was used with all participants to measure their level of hope. The scale is comprised of 29 questions "covering six dimensions and provides detailed information on different aspects of hope. It is specifically developed to measure hope in individuals suffering a crisis such as a diagnosis of cancer" (p. 27). The scale is of Likert format and a respondents' score can range anywhere from 29 to 116, where a lower score indicates a lower level of hope and a higher score indicates a higher level of hope.

Along with ways to measure hope, the literature also provided some methods to use to promote and foster hope with this population. A couple methods discussed by Johnson (2007) include doing activities such as writing letters to leave a legacy, or conducting a life review. A life review, according to Johnson (2007), allows the individual to have “hope because they were able to acknowledge past achievements and their valuable contributions to life and the lives of others” (p. 456). One last method discussed by McClement and Chochinov (2008) is a form of psychotherapy called “dignity therapy,” with an overall goal of lessening suffering and helping provide a sense of meaning for the patient (p. 1170).

Faith-Based Services among Cancer Patients

Along with hope being shown to have a positive effect on cancer patients, research studies have suggested that faith and faith-based services may be a component of healing within this population. It was noted in one article that “there is a protective factor of religion to health” (Meisenhelder & Chandler, 2002, p. 243). *Spirituality* has been defined as a “personal search for meaning and purpose in life, connection with a transcendent dimension of existence, and the experiences and feelings associated with that search and that connection” (Peterman, Fitchett, Brady, Pharm & Cella, 2002, p. 49). The effect of the utilization of faith and faith-based services has further been shown by three studies (Dann, Higby & Mertens, 2005; Meisenhelder & Chandler, 2002; Whitford & Peterson, 2008) which are described below.

In a study conducted by Whitford and Peterson (2008), spirituality and quality of life were examined among 490 participants, all of whom had a cancer diagnosis. The age of the participants was not noted. The participants completed questionnaires and

provided demographic, disease, religious affiliation, and treatment information. Overall, it was found that people with higher meaning in their life would carry on as they had before their diagnosis “with a positive outlook and hope” (Whitford & Peterson, 2008, p. 1124). Faith did not seem to have any impact on how patients experienced pain, but “Spiritual well-being was most highly related to fighting spirit, followed closely by a negative relationship with helplessness/hopelessness” (Whitford & Peterson, 2008, p. 1126). This study shows the positive relationship between hope and spirituality, and leaves room for more exploration, specifically in relation to the elderly population.

In another study, Dann, Higby, and Mertens (2005) examined how faith and faith-based services were utilized within hospital settings by cancer patients, their families, and other members of their support system. According to the authors, research has shown that both religion and spirituality are positive coping mechanisms for handling the stress that goes along with a cancer diagnosis (Dann et al., 2005). It was noted that spirituality delivers “strength, comfort, and hope” to cancer patients (Dann et al., 2005, p. 1). For the purposes of the study, a spiritual intervention was developed in which a nondenominational worship service was provided for patients, their families, and other members of their support system. The themes of “surrendering fear, hope, peace, feeling God’s love, and the importance of community” were communicated in the services through a variety of methods (Dann et al., 2005, p. 2). Overall, there were a lot of positive reactions. The themes and methods were well received by the participants, and the majority of participants said the service was helpful. In relation to the overall spiritual intervention, participants also reported that “the partnership between hospital and church was a positive development, leading to an enhanced recognition of patient

needs” (Dann et al., 2005, p. 4). This study shows the positive impact of utilizing faith-based services, but does not look at this impact specifically in relation to the elderly population, which supports the need for further research.

Meisenhelder and Chandler (2002) examined the effects of religion and spirituality in relation to health management. Meisenhelder and Chandler (2002) further examined the relationship between religious practices and various areas of health, from physical health to mental health. For the study, 250 individuals over the age of 65 were given a health survey and also asked questions related to their religious practices, the importance of their faith, and how their faith helps them cope. Overall, Meisenhelder and Chandler (2002) found that those who place higher value on their faith experience less anxiety and depression; therefore, showing that faith has an effect on overall mental health. This study shows that elderly individuals utilize their faith and religious practices, and that this can have an effect on health; whether mental or physical. This study leaves room for more exploration in relation to elderly individuals with cancer.

Implications for Social Work

Social workers in medical settings have a lot of involvement with cancer patients and their families, and thus, having knowledge of the roles of hope and faith-based services with this population is very important. Esbensen and Thomsen (2011) point out that there is a “necessity for health care professionals continuously to recognize the situation of the elderly individual with cancer in order to counteract the reduction of QoL (quality of life) that may occur and to support their hope” (p. 31). Social workers are a particularly good fit in working with cancer patients because social work education informs and prepares social workers to look at an individual in relation to their

environment and the ways in which multiple factors in their lives can have an impact on the individual.

The literature shows a strong link between having hope, utilizing faith-based services and positive outcomes with cancer patients. The role of hope and faith-based services will be further explored by interviewing hospital social workers to discuss their professional experiences and perceptions of these aspects in relation to elderly individuals with terminal cancer. The focus and main question of this paper is: How do hospital social workers see elderly individuals with terminal cancer utilize hope and faith-based services to help in their healing process?

Conceptual Framework

This section will outline Erik Erikson's developmental theory consisting of stages of psychosocial development, discuss the theory in relation to elderly individuals with terminal cancer and applied through the intervention of a life review. This section will also discuss the researcher's personal experience with a family member who has cancer as well as her professional experience in working with individuals with cancer. These three areas will be examined in order to deepen the understanding of the developmental stage of elderly individuals and how this could impact their view of their life and accomplishments, as well as how they adjust to a terminal cancer diagnosis.

Psychosocial Theory of Development

Eight stages of man. Erik Erikson's theory of psychosocial development consists of eight stages, which he called the *Eight Stages of Man* (Foyle & Hostad, 2004). Erikson's theory, specifically in the first five stages, could be viewed as a continuation of Sigmund Freud's five stages of psychosexual development, which cover development from birth through adolescence (Slee, 2002). Freud's stages of psychosexual development correlate with the development of a certain part of the body, or pleasure centers, and are biologically determined. Freud believed that if a child experienced difficulty in resolving the task associated with each stage, this would result in fixation, or being focused, on that stage or corresponding part of the body, which would then result in an unhealthy personality (Pressley & McCormick, 2007).

It is important to understand some of the fundamentals of Erikson's theory as well as some differences between his and Freud's theory. One significant difference between Erikson's and Freud's theories is that Erikson focuses on psychosocial development

across the lifespan, as well as development of identity, not just on sexual development, as Freud did (Foyle & Hostad, 2004). Each stage of development that Erikson outlines consists of a developmental crisis, or task, to be accomplished, and the failure to accomplish each task has consequences, as noted by Greene in that, “Erikson emphasized that one stage of development builds on the successes of previous stages. Difficulties in resolving earlier psychosocial issues may predict difficulties for later stages” (2008, p. 93). Based on the idea that developmental stages build upon each other as Greene (2008) notes in relation to elderly individuals with terminal cancer, it is important to understand how earlier phases in life could impact their ability to cope with their current situation. Even though an elderly individual is in the last of Erikson’s developmental stages, they may have progressed through the previous developmental stages inappropriately, and this could result in significant difficulty in the final stage of development in old age.

The first seven stages of Erikson’s developmental theory will be briefly discussed, but the primary focus of this conceptual framework, as well as the research, is the final stage, which takes place during late life.

The eight stages of psychosocial development. The eight stages of psychosocial development created by Erikson will be outlined as discussed by Uba and Huang (1999), including each core task, along with what successful and unsuccessful completion entails. During the stage of *trust vs. mistrust* (age birth to one year), completing the developmental task of learning to trust others through getting basic needs met means the individual will learn to trust others and “expect life to be pleasant” (Uba & Huang, 1999, p. 330). If this task is not accomplished, it will result in the individual not being able to trust others. The second stage of *autonomy vs. shame and doubt* (ages one to three),

involves completing the developmental task of controlling and directing one's own behavior. Completion of this task means the individual will become independent, and non-completion will result in "[learning] self-doubt and shame" (Uba & Huang, 1999, 319). During the third stage of *initiative vs. guilt* (ages three to five), completing the developmental task of controlling one's own behavior and acting appropriately in a given situation means that the individual will develop initiative. If this task is not completed, the individual will "feel irresponsible, anxious, and guilty" (Uba & Huang, 1999, p. 330). The fourth stage of *industry vs. inferiority* (ages five to 12) involves completing the developmental task of learning new skills and knowledge, as well as gaining new information and knowledge. If the developmental task is accomplished, it means the individual will feel competent in his/her work, and failure to complete this task will result in feeling incompetent. The fifth stage of *identity vs. role confusion* (adolescent years) consists of the developmental task of figuring out who one is as an individual and what he/she wants out of life. If this task is completed, the individual will develop a sense of identity. If this task is not completed, the individual may become confused or withdrawn. In the stage of *intimacy vs. isolation* (early adulthood), the developmental task at hand is that of being able to share the previously gained sense of identity with another individual within the scope of a committed relationship. Completion of this task results in a committed relationship, and failure results in isolation.

The seventh stage of psychosocial development is that of *generativity vs. stagnation* (middle adulthood). This stage involves being able to be "creative, productive, and nurturant of the next generation" (Uba & Huang, 1999, p. 352). If completion of this task is successful the individual will reap benefits both in relation to

him/herself, as well as others in their life and future generations. Failure to complete this task will result in the individual being focused on themselves and feeling as though they have made no contributions for future generations, and seeing no benefit to him or her being alive (Uba & Huang, 1999). This stage also involves changes to one's previously established lifestyle, including planning for retirement and later life (Bunker-Rosdahl & Kowalski, 2008). If someone in this stage receives a terminal cancer diagnosis, this could trigger him or her to begin thinking about their own mortality and may change how they envision later life for themselves. The final stage of Erikson's psychosocial developmental theory will be discussed and summarized in relation to the proposed study.

Theory Applied to Elderly Individuals with Terminal Cancer

Even though elderly individuals may have received their cancer diagnosis when in middle age, the particular focus for this research will be elderly individuals who receive a diagnosis of terminal cancer in old age.

As noted earlier, Erik Erikson's theory of psychosocial development consists of eight stages and a core task is to be accomplished during each stage. Haber (2006) notes, "Each of Erikson's developmental stages embodies a fundamental issue that challenges the individual who attempts to resolve it and move on to the next stage" (p. 157). This implies that an elderly individual may be elderly in terms of years lived, but they may not have mastered the core task of an earlier developmental stage. This could result in their life course having not progressed as developmentally appropriate. It is also important to note that although each of the previously described stages involves a crisis specific to the particular stage and age, as Uba and Huang (1999) note, the crises described can happen

at different times for different people, and can also happen more than once for some individuals. This crisis could also add to the complexity and difficulty that an elderly individual could experience when attempting to cope with a terminal cancer diagnosis.

The focus here will also be on the stage of *integrity versus despair* (old age). This stage can be characterized by an imbalance between “ego integrity and despair or disgust with life” (Forte, 2007, p. 301). Forte (2007) defines the *ego* as the organizing part of the psyche, as well as the mediator between both impulses and demands. It is noted that Erikson “characterized ego integrity as the acceptance of one’s life cycle and personal history. . . and the ability to defend oneself against physical or economic threats” (Forte, 2007, p. 301). Uba and Huang (1999) describe the stage of *integrity vs. despair* as “the issue is whether a person will reach wisdom, spiritual tranquility, a sense of wholeness, and acceptance of his or her life” (p. 352). Uba and Huang (1999) note that if an elderly person is able to accomplish these things, they will “enjoy life and not fear death,” but if they are not able to accomplish these things, “they will feel that their life is empty and will fear death” (p. 352). According to Foyle and Hostad (2004), some normal changes that accompany old age include expected changes in health, retirement, and decrease in social activity, but these may happen at a faster pace for individuals with a terminal illness. Elderly individuals with terminal cancer may be having difficulty reaching or achieving a sense of wholeness, and have difficulty accepting both their diagnosis and their life as a whole. As a result of this, the individual may not be enjoying life, be able to see their purpose, and may be fearful of death.

Erikson’s developmental theory can be applied to elderly individuals with terminal cancer. One intervention that has been employed to assist elderly individuals in

the stage of *integrity vs. despair* is that of a life review or reminiscence. Haber (2006) notes, "Erikson viewed life review or reminiscence as vital to the task of stage eight, the stage associated with old age. Life review can help older individuals acquire ego integrity and avoid despair" (p. 157). A life review, according to Haber (2006), involves creating acceptance of one's life through examining memories and "[providing] a harmonious view of past, present, and future" (p. 157). Some studies that Haber (2006) mentioned explain that life reviews can have positive impacts on things like ego integrity and life satisfaction. Conducting a life review, both with individuals who have a terminal illness regardless of age and elderly individuals who do not, clearly has benefits. For example, Foyle and Hostad (2004) assert that these benefits include "reaffirmation of self-esteem and identity, reduction in feelings of loss and isolation, and renewed emphasis on the positive aspects of their life" (p. 166). These benefits clearly display the importance of utilizing the intervention of a life review with elderly individuals with terminal cancer.

Professional Lens

As a researcher, I have not had any professional experience working with either the elderly or terminal cancer patients, but I wish to pursue a career in either of these fields. The hope is that this research will give me good insight into how to work effectively with these populations. Although I do not have professional experience working with either the elderly or terminal cancer patients, I feel that my social work education and field experience have prepared me to work with these populations in the following ways: I am able to view an individual within the context of their environment and other influences; I have knowledge of, and am able to, work from multiple theories

such as systems, person in environment, cognitive behavioral, solution-focused, and others; I am able to conduct a clinical assessment and adjust interventions appropriately; and, I have a high level of compassion, empathy, and a strong desire to help others. Overall, my personal experience and interest in working with cancer patients has driven my professional interest in the topic of this research.

Personal Lens

My personal experience ultimately drives my interest in this area. One of my immediate family members recently received the diagnosis of cancer. The family member was in his fifties at the time of diagnosis. Seeing how he went through treatment, and the internal resources and strengths he had raised my curiosity regarding how an elderly individual would go through the same process. One strong bias I have is that I truly believe in the power of positive thinking and believe that having hope and faith-based services to utilize throughout the healing process can greatly affect outcomes. This bias has steered this research project in the direction of looking at these resources regarding an elderly individual with terminal cancer, as utilized in the healing process.

Methods

Research Design

A qualitative research design was used to collect data for this study. A qualitative design was employed in “an attempt to gain access to that personal, subjective experience” (Monette, Sullivan, & DeJong, 2011, p. 225) among respondents. This study’s focus on elderly late-stage cancer patients was chosen in light of the growing elderly population and literature emphasizing the utilization of healing processes within hope and faith-based services. The goal of this study was to better understand how social workers that work with geriatric late-stage cancer patients perceive these individuals’ utilization of both hope and faith-based services in healing. Semi-structured interviews were conducted in this research and nine questions were asked of participants that described their role as a hospital social worker, the services they provide, some traits and characteristics they see among cancer patients and/or the elderly, and how they see the elderly and/or cancer patients utilize hope and faith-based services in their healing process (see Appendix A for a list of interview questions).

Recruitment

This researcher utilized both a convenience sample and a snowball sample of hospital social workers in a large Midwestern city. This large city was chosen due to the number of large hospitals in this region of the state. The sampling strategy of a convenience sample was used because difficulty was anticipated in locating eight hospital social workers who have worked with both terminal cancer patients and elderly patients in a medical setting.

The convenience sample was obtained through the placement of cold calls to social workers whose contact information had been made publicly available via the Internet. The snowball sample was obtained when each participant was asked at the conclusion of each interview if she could identify anyone else who would meet the criteria for the study (Monette, Sullivan, & DeJong, 2011).

Due to recruitment challenges, inclusion criteria changed somewhat from the time this study was conceptualized to when the participant interviews were completed. Initially, social workers who worked (either in the past or present) with elderly individuals with terminal cancer that were willing to share their perspectives regarding how this population utilizes hope and faith-based services in the healing process were recruited for this study. However, when this researcher encountered difficulty locating participants who had specifically worked with terminally ill elderly cancer patients in hospital settings, inclusion criteria for recruitment was expanded to include social workers who possessed experience working with adult cancer patients, and/or those who had experience working with elderly cancer patients in any medical setting (e.g., outpatient cancer clinics). Exclusion for this study was modified slightly to exclude social workers who lacked experience working with the elderly in a medical setting or who had not worked with cancer patients over 18 years of age.

Initially, participants were recruited vis-à-vis recruitment flyers that described the research study (see Appendix B). Flyers were distributed to professionals in the field (hospice social workers, a chaplain, and social workers with past medical experience) who were likely to know potential respondents. The flyer was also posted near hospitals or potential locations where hospital social workers frequent. The researcher also placed

cold calls to hospital social workers who post their contact information publicly. Participants received a \$10 Target gift card in appreciation of their participation.

Protection of Human Subjects

This year-long research project, a graduation requirement for the Masters of Social Work program at University of St. Thomas and St. Catherine University, was approved both by this writer's committee and by an Institutional Review Board. Once participants consented to participate in the study, they received letters of introduction that outlined details of this study (see Appendix C). Each participant received a copy of the Institutional Review Board approved consent form (see Appendix D) as well as the interview questions prior to the interview via email. Each participant had the opportunity to read over these materials prior to the interview and the consent form was reviewed verbally with each participant at the time of the interview. Participants were also informed that the interview would be audio recorded.

Prior to interviews, participants read and signed consent forms. This form discussed steps that had been taken to protect participant confidentiality, risks and benefits of participation in the study, as well as the participants' right to end the interview at any time. Lastly, the consent form outlined what would happen to the data retrieved after completion of the research study, as well as where the data would be stored.

Prior to interviews, participants were informed of the risks and the voluntary nature of participation in the study. Social workers were told that while participation in this study posed minimal risk to them, they may experience slight feelings of discomfort when discussing difficult subjects (e.g., patients they had worked with closely dying from cancer). Each participant was given a resource guide (see Appendix E) that listed mental

health and counseling resources in order to further minimize potential harm done by participating in the research study. Social workers were told that participation in this study was completely voluntary and that they could back out of the interview at any time. Participants were also told that they were not required to answer all of the questions if they did not wish to, and could go into as much or as little detail as they wished. Risk was also minimized through the researcher interacting with both the University of St. Thomas Institutional Review Board and a professional research committee.

Participants were informed that there would be no consequence if they chose not to participate, and relations with the researcher, St. Catherine University and University of St. Thomas would not be affected. Care was taken to ensure confidentiality by limiting viewing of the data to the researcher, her research advisor, a research assistant who signed a confidentiality agreement form, and the Institutional Review Board.

Participants were given the opportunity to express a desired location for their interview to take place, and given the opportunity to conduct the interview via telephone, as to ensure comfort on the part of the participant. Each participant was also informed that they had one week after the interview took place to remove themselves and the information they provided from the research process.

Data Collection

A semi-structured interview, lasting no longer than one hour, was conducted as the primary instrument for collecting data for this study. Nine open-ended questions were prepared by the researcher and reviewed by the researcher's professional research committee and Institutional Review Board prior to the interview taking place. The questions were created by the researcher based on a review of the literature as well as

personal experience, and were intended to give the participant the freedom to offer as much or as little information as they felt comfortable providing.

After completion of each interview, a research assistant, who signed a transcriber confidentiality agreement form, transcribed each interview on a password-protected computer while maintaining proper and secure storage of all interview information. Minimal identifying information was provided to the research assistant. The transcribed information was then transferred back to the researcher for data analysis purposes. The audio recording and transcription information were deleted from the research assistant's password protected personal computer upon completion of transcription.

After transcription, the data was stored on a secured external hard drive, and will be deleted from the hard drive three years after completion of the research. Each participant's signed consent form, and any written notes, were stored in a locked file cabinet in the researcher's home. These consent forms will be shredded at the same time the transcription material is deleted from the researcher's computer hard drive.

Data Analysis

To review each transcript, the researcher used a conventional content analysis, or a "grounded theoretical approach" in which the raw data was used to generate themes in order to identify similarities and differences in the information obtained (Berg & Lune, 2012, p. 352). This method was used in order to reduce and to simplify the data while "retaining words and their essential meaning" (Monette, Sullivan, & Delong, 2011, p. 434). The researcher started with open coding, or reading the transcription, and identifying themes in this process. The researcher then went back through the transcription with the themes previously identified.

Sample

Seven hospital/medical social workers participated in this study. Each participant possessed experience working with adult and elderly cancer patients in the terminal phase of their illness. The demographics of the research participants included seven female social workers of varying ages. The amount of experience working with the cancer patient population ranged amongst participants; anywhere from two or three years of experience to approximately thirty years. Three participants were currently working with cancer patients in a cancer center setting, and four of the participants spoke about past experience working with cancer patients in a hospital setting. Overall, the participants represented five different medical settings, all of which were either hospitals or cancer care clinics.

Social workers who participated in this study described their roles in similar ways, such as connecting patients and families with resources, or responding to new patient referrals. One participant summarized various aspects of her role when she shared,

I would work with them to offer support and do psychosocial assessments, work with their families and loved ones to identify areas of concerns. . . and to link them to resources to help them after they left the hospital whether it be going home with a variety of home care services, hospice services, helping them get in touch with American Cancer Society and accessing funding for potential services. And. . . facilitating family care conferences.

These roles were also discussed by other participants along with roles such as assisting in adjusting to an illness, providing end of life counseling, and helping families make

decisions. There were also participants who had involvement with discharge planning and conducting various support groups. Two participants provided psychotherapy services to cancer patients as well.

Findings

The purpose of the current study was to examine medical social workers' perspectives regarding how elderly individuals with terminal cancer utilized hope and faith-based services in their healing process. The dominant themes that emerged in this research were (1) hope varies (2) why hope differs, and (3) faith and healing. Within the theme of hope varies, the two subthemes that emerged include (1-a) the presence of hope, and (1-b) the absence of hope. Two subthemes present within the theme of why hope varies include (2-a) age differences, and (2-b) changes in perspective. Lastly, within the theme of faith and healing, the two subthemes that emerged were (3-a) the ability to be at peace, and (3-b) the belief that there is something more or better to come. Table 1 represents a condensed presentation of themes, subthemes, and gives corresponding example quotations.

Table 1

Themes, Subthemes, and Sample Responses from Participants of This Study

Themes and Subthemes	Sample Responses
(1) Hope varies	
(1-a) The presence of hope	“People who are hopeful see something positive going on for them or maybe even there’s clarity about something. . . I have a name for what’s going on. . . now I know I have a certain treatment plan”
(1-b) The absence of hope	“When you take away hope there’s nothing.”
(2) Why hope differs	
(2-a) Age differences	“If I was 85, my hope might be to be comfortable. I hope that I told my family that I love them, that they know. I hope just a different hope.”
(2-b) Changes in perspective	“Hope is one of those things that can... change depending on the stage of illness a person is in, and at one point the hope may be for a complete cure, and other times, it may be for a peaceful and comfortable death.” “There was a relationship between hopefulness and acceptance of reality.”
(3) Faith and healing	
(3-a) The ability to be at peace	“Faith, and...maybe being at peace with...whatever road you’re on, I think certainly is linked. . . connect it with faith and them...being at peace with whatever the journey is. . .”
(3-b) The belief that there is something more or better to come	“I do feel there’s a level of comfort when people have a bit more a faith background. . . I’ll be in a better place is really, I think, that’s very comforting for people. It sort of eases that level of distraughtness. . . their journey here on Earth is sort of coming to an end.”

Note. This table includes the themes and subthemes that evolved from this study. Sample responses for each theme are provided in this table.

Hope Varies

The presence of hope. Participants discussed both the presence and the absence of hope in their interviews, and noted what each can look like in cancer patients. One dynamic that emerged from participants' reflections regarding the presence of hope was that there was an existing relationship between the presence of hope and a cancer patient's ability to see the positives of their situation. Four of seven participants discussed this dynamic, particularly mentioning patients seeing positive aspects within knowing their diagnosis, having a treatment plan, having clarity, and being determined to come out of the situation well. One participant commented on this dynamic when discussing how she identifies hopeful versus hopeless patients when she said, "People who are hopeful see something positive going on for them, or maybe even there's clarity about something. . . I have a name for what's going on. . . now I know I have a certain treatment plan." Another participant commented on cancer patients' ability to see the positives and reflected that, "Where as if people are hopeful they have a smile on their face, and they are determined. They are going to beat this, and no matter what, they're going to come out well on the other end."

In addition to the discussion of the innate relationship between the presence of hope and one's ability to see the positives, the social worker's role in assisting patients in seeing the positives was also mentioned. One participant noted that there was a link between the presence of hope and a cancer patient's ability to see the positives in their situation when she spoke to a way that social workers can help cancer patients identify the positives in their experience. She further articulated this through stating,

Focusing on ways to keep them to continue to be hopeful and continue to see that their cancer is a piece of them, it doesn't define them, and what important lessons can you learn about life through your cancer experience. . . what miraculous things that have happened from their cancer experience.

The absence of hope. Aside from the presence of hope, five of seven participants discussed a relationship between the absence of hope and healing, and mentioned what this can look like in cancer patients. For example, when adding additional comments regarding support groups, one respondent commented on the overall idea of the absence of hope at the end of her interview when she said, "When you take away hope, there's nothing." She went on to say that she has heard patients say this both on an individual basis with her as well as within support group settings. When discussing the absence of hope as a factor in healing, one respondent shared that what she has noticed in some instances was that without hope some patients have difficulty engaging with treatment. She specifically stated, "Without hope sometimes these are people who decline to work with therapy, who decline to work with medications, decline further evaluation of whatever medical condition that is going on." This same participant expanded by adding that the absence of hope can affect how a cancer patient moves forward. She reflected that,

Folks that are hopeless are. . . actively suicidal. . . unable to kind of have any source of energy to kind of address emotional things, or even sometimes, it's those folks, too, who seem to have a real difficult time with kind of making decisions about treatment options and being able to move and engage with those things too.

Poor mental health was also discussed in relation to an absence of hope by three of seven participants as it related to patients' negative responses toward treatment. It was found that patients' mental health, either past or present, may impact patients' level of hope and could, in some cases, impact healing. It was also noted that in some instances patients' mental health needed to be further managed, and that anti-depressants or anti-anxiety medications were commonly used in their treatment regimens. Mental health specific responses came about when participants were asked how they identified and worked with hopeful patients versus hopeless patients. One participant, when discussing mental health and its impact, stated, "I think the people who have lived lives of fear and anxiety are going to bring a lot of that to dealing with their cancer and probably not get to a healing point." Another participant commented, "If you don't have hope, so often there's this level of despair or apathy. Hope. . . helps us get up in the morning and have energy to do something. . . small or large." It was also stated by a third participant that, "Sometimes people who are hopeless are depressed, so it's a matter of figuring out how to get their depression a little further managed." This same participant went on to say, "Sometimes people that are hopeless. . . either they believe they have a fatalistic kind of sense that I'm just going to die anyways."

Why Hope Differs

Age differences. In addition to discussing hope as either being present or absent, participants also referenced hope as being variable, both as a result of patient's age as well as a change in what was hoped for. When discussing the differences of hope, two respondents discussed age as an influence on levels of hope among cancer patients. Participants discussed the age of cancer patients they had worked with in relation to how

they saw the patient's level of hope evolve, if at all, throughout either the course of the individual's illness or the social worker's time working with them. One participant also reflected on what influence age has on hope when she added comments at the end of her interview. One of her comments was,

Especially with the elderly, that at the end of their life or with their cancer diagnosis at age 85, they might just be OK not being hopeful to get better. . . so maybe identify hope, hope for what, hope to be cured, or hope to be comfortable. . . their hope, I would say, isn't necessarily a hope to be cured, but it could be a hope to be comfortable.

This same participant further discussed the influence of age when she said, "If I was 85, my hope might be to be comfortable. I hope that I told my family that I love them, that they know. I hope, just a different hope." This participant also noted, "The elderly, they kind of had a strong faith that gave them that hope and comfort or they didn't." A second participant also supported this influence of age when she shared details around what hope has looked like in her practice with younger cancer patients. She shared,

For others, particularly young people where it...comes out of the blue, it can be very frightening and scary, and for them it's hard to be hopeful, especially if it's something that carries with it a very bad prognosis.

Changes in perspective. The idea that hope can differ due to changes in the perspective of cancer patients, and specifically, the idea that a cancer patient's level of hope can be variable in the sense of hoping for something other than a cure arose in many interview transcripts, and was supported by six out of seven participants. Participants commented on the idea of changes in perspective in response to being asked how they see

cancer patients' levels of hope evolve, if they have noticed a relationship between utilizing faith-based services, the level of hope an individual has and their healing process, and if they view these things as part of the healing process for cancer patients. Participants noted that the hope cancer patients experience can change depending on what stage of cancer an individual has or can change throughout the course of their illness. Hope was discussed as being variable or changing in relation to what cancer patients were hoping for, which can be a host of things besides a cure. The hope to have time, to feel comfort, to experience a lack of pain, to remain in control, and maintain an ability to make decisions were all discussed as taking the place of hope for a cure. For example, one participant illustrated the hope for time by commenting,

What I have found over my work with terminal patients is that hope changes as disease progresses. So I do believe that hope remains even as maybe their condition continues to deteriorate. So instead of hoping for a cure. . . they're hoping for no pain. Instead of hoping. . . they'll make it ten years, they're hoping to make it to a daughter's wedding. . . Their hope changes as their condition changes.

Another participant shared an example of how patients hoped they would not be in pain by saying,

When they feel like they can't fight anymore, they feel like they're letting their family down and their friends down, because they're fighting, and they don't have anymore, and what my wording often is, I don't see it as giving up hope. I think you're just changing what you're hoping for. . . At one point, you're hoping for a

cure, and now maybe you're hoping not to be in physical pain, not be in spiritual pain, not be in psychological pain. So you're just changing the focus.

In addition, participants also referred to patients as hoping to have some sense of control or comfort regarding their death. For example,

Hope is one of those things that can...change, depending on the stage of illness a person is in, and at one point the hope may be for a complete cure, and other times it may be for a peaceful and comfortable death.

Another participant commented on the hope to be in control and be able to make decisions when she discussed one patient who, "Kept hope that despite not finding a cure there's still hope that you are going to have some control over the end of your life and still be able to make some decisions."

One participant in this study mentioned the relationship between the presence of hope and cancer patients' acceptance of reality, which also speaks to why hope differs. Although only one participant spoke to this relationship, this theme is of note because she referenced it multiple times throughout her interview. In the first instance, she was asked if she noticed any relationship between a patient's level of hope and their healing process, and she responded that at a certain point some patients shift their focus more to looking for comfort and added, "Hope is very intertwined with. . . acceptance of reality." This same participant also spoke of this relationship when asked how she identifies hopeful cancer patients versus hopeless cancer patients. She stated, "There was a relationship between hopefulness and acceptance of reality." The last instance in which this same participant spoke to the link between hope and acceptance of reality was when she was asked how she saw cancer patients' levels of hope evolve. She responded to this question

with, “You go through the stages like any sort of loss or grief. . . and then you eventually come to a place where you’re more accepting of what’s happening.”

Faith and Healing

The ability to be at peace. The relationship between an individual with cancer having faith and/or utilizing faith-based services and being at peace was fairly prevalent throughout this study. This relationship was supported by four of seven participants, each of whom spoke about a relationship between utilization of faith and faith-based services and an individual’s ability to be at peace. Participants discussed this relationship when asked if they saw a relationship between the use of faith-based services, an individual’s level of hope, and that individual’s healing process, or if they saw hope or faith-based services being a component of the healing process for cancer patients. Participants reflected that the use of faith and/or faith-based services promoted the manifestation of an inner peace. For example, one participant said, “Faith and. . . being at peace with. . . whatever road you’re on, I think certainly is linked. . . connect it with faith in them. . . being at peace with whatever the journey is.” Another participant added in relation to faith and its influence on healing that,

It doesn’t always have to be physical healing. I think that’s what’s wonderful about it is that they get this sense of hope and spirituality that they didn’t have before. I think that, in the end, it doesn’t matter if they’re cured or not cured because they kind of feel their soul, you know, they’ve gotten their inner peace.

A third participant further noted this relationship between faith and being at peace by commenting, “What I see sometimes is for people who have that, that hope through their

spirituality. I feel like they are just, are more at peace sometimes. . . They can find that inner peace.”

The belief that there is something more or better to come. The belief that there is something more or better to come was referenced in relation to having faith and/or using faith-based services and was discussed by four of seven participants. Participants talked about cancer patients’ belief that there is something more or better to come in response to being asked if they see faith-based services as being a component of the healing process for cancer patients, and if so, how this was evident or made manifest in their work. Participants discussed faith and/or faith-based services as being part of healing, as aiding in the belief of something more or better to come, and that this belief could be comforting or calming to patients. One participant articulated this effect by commenting,

I do feel there’s a level of comfort when people have a bit more a faith background. . . I’ll be in a better place is really, I think that’s very comforting for people. It. . . eases that level of distraughtness. . . Their journey here on Earth is sort of coming to an end.

Another participant further noted the idea of faith and the belief of something more or better to come providing a comforting or a calming effect by stating,

I definitely think it gives them some. . . like a calming over them. . . just that comfort that ultimately God is in control, and they’re going to go to heaven, and I think especially with the elderly, we heard a lot of, I’ve lived a good life. . . and a lot of them, I think, had that acceptance of if this is my time to go. I lived a good life. God’s been in my life, and. . . now I get to go to heaven.

Another participant further articulated these positive effects of a cancer patient having the belief that there is something more or better to come, when she commented, “For a lot of people, I think having a sense. . . that there is something more to come, that can be very helpful for some people.”

Discussion

The purpose of this research study was to explore how hospital or medical social workers view how elderly individuals who have terminal cancer utilize hope and faith-based services to help in the healing process. It should be noted that participants of this current study spoke to their experience working with cancer patients of all ages, and in all stages of illness, not only elderly individuals in the terminal phase of illness. Although the overall findings from this study support previous research and existing literature, this study also shows the need for further research in the following areas: the use of hope and faith-based services in healing, specifically related to elderly cancer patients; how mental health impacts levels of hope; and how age influences levels of hope within cancer patients. These implications will be described further in the recommendations for future research section of this discussion. Additionally, this research study points at social work practices that could be implemented, and/or strengthened, in relation to working with cancer patients, which will be discussed in the implications for social work practice section of this discussion. This discussion section will compare and relate ideas found in this research study to ideas found in the existing literature regarding the topics of hope and faith-based services, both in general and in relation to cancer patients.

Hope Varies

The presence of hope. Participants of this study discuss the idea of hope varying in the sense of being present or absent. For example, participants discussed the idea that hope can aid in an individual's ability to see the positives. The idea of the presence of hope, and its relation to being able to see the positives in a situation, as discussed by participants supports the current literature in this area. Specifically, McClement and

Chochinov (2008) note, “The findings of many studies demonstrate that living with hope is a significant factor that assists individuals to adjust to their cancer illness, reduce their psychological distress and enhance their psychosocial well-being and quality of life” (p. 1170). This statement by McClement and Chochinov (2008) indicates that the presence of hope is a positive factor in the healing of cancer patients. Similarly, in the current research, participants speak to the idea of adjusting to a cancer illness in relation to being able to see the positives in a situation, and this idea is spoken to in the sense that the presence of hope aids in an individual’s ability to have clarity, and to see the positive in knowing their diagnosis and having a treatment plan. One participant mentions that individuals who have lived a life filled with some level of hope will often carry this forward in facing the challenges brought forth by their terminal illness, thus possibly helping them adjust to their cancer illness and reducing psychological stress.

Participants not only recognize that hopeful cancer patients are better able to identify the positives in their negative situation, but they also recognize the importance of developing and fostering this ability in cancer patients no matter their situation. One participant in particular notes this importance when she shares the significance of helping cancer patients identify that their cancer does not define them. She would also work with patients to identify miraculous things that have happened, or lessons they have learned about life through their cancer experience. Overall, it is articulated through participants’ statements that people who are hopeful are better able to see the positive in a negative situation or a potentially negative outcome. These findings further note the need for ongoing assessment of patients’ levels of hope.

The absence of hope. Not only was the presence of hope discussed in this study, but the absence of hope was also referenced in relation to healing. The relationship between the absence of hope and the healing process is referenced in two different ways by participants throughout the study; making treatment or healing more difficult, and in relation to a patient's mental health. Findings of this study support the findings of Elliott and Olver's (2007) study in which it was noted by one participant that the absence of hope has a negative impact on a cancer patient's ability to engage with treatment and can result in cancer patients giving up. The idea of the absence of hope making treatment or healing more difficult comes forward in this current study through statements illustrating the negative impact that the absence of hope can have on one's healing, or more generally, how an individual, who has an absence of hope, will negatively manage his/her illness. Participants made statements relating the absence of hope to patients having difficulty engaging with treatment, therapy, or medications, and also refer to cancer patients who have an absence of hope as having a more difficult time making decisions regarding their treatment. These findings contribute to the knowledge base regarding the negative impacts that the absence of hope can have on a cancer patient's healing.

Participants bring the second idea of the absence of hope being related to poor mental health to light in their discussion of mental health, both in the past and present. The current state of literature does not reflect studies that examine this particular relationship. Within this current study, patient's mental health is discussed as being a factor in terms of both the level of hope an individual has along with their healing process. For example, the absence of hope is related to depression, or other issues regarding fear and anxiety, and it is noted by one participant that sometimes a cancer

patient's depression has to be managed before moving forward with anything else. In addition, a cancer patient's mental health is mentioned, in some cases, as being related to not reaching a healing point. The findings note that poor mental health can play into an absence of hope, with this absence of hope leading to difficulties with treatment in some cases. Since there is no previous research on this relationship, further research will be needed to either support or contradict these findings. One speculation as to why the relationship between levels of hope and mental health is not in the reviewed literature could be due to the complexity of the relationship.

The general idea of the absence of hope is found to originate from various sources, both within current literature as well as in this research study. For example, Dickerson et al. (2006), in a study that examined social support among cancer patients, discuss this absence of hope stemming from sources such as an individual with cancer reading something negative about their diagnosis, or getting bad news from a doctor. Conversely, in this research study, the absence of hope is mentioned in some instances as being a result of poor mental health in contrast to reading or hearing bad news as was found in Dickerson et al.'s (2006) research.

Just as the sources of an absence of hope can be different from one person to another, what a cancer patient subsequently does in response to this absence of hope may also vary. Dickerson et al. (2006) discussed the absence of hope an individual experienced resulting in him or her turning to other sources (e.g., the Internet) to seek out hope through receiving alternate perspectives, to hear other individuals' stories, or to partake in online support groups. In contrast, findings of this research study differ from those in previous research. It was found here that some cancer patients have more

negative responses to their absence of hope and may have more difficulty engaging with treatment due to reasons such as overall absence of hope or poor mental health. Findings from this research study contribute to knowledge that individuals may respond to the absence of hope differently, in this study, more negatively.

Why Hope Differs

Age differences. The idea that hope can differ may be seen throughout this study in a variety of statements, both in relation to age, as well as individuals changing their perspective and hoping for something other than a cure. The idea that hope can differ and may be dependent on an individual's age is found in this study, but the difference in hope in relation to various ages is not specifically studied or noted in the literature reviewed. Erik Erikson's *Eight Stages of Man*, which outlines stages of psychosexual development and developmental tasks that correspond with age, may connect with explanations given by social workers in this study who discuss differing hope in relation to age. For example, Erikson's developmental theory offers an explanation that even though an elderly individual is in the last of Erikson's developmental stages, they may have progressed through the previous developmental stages inappropriately and may be fixated on an earlier stage of development. This could result in significant difficulty in the final stage of development in old age and may affect an individual's attitudes in relation to hope. This illustrates that if an elderly individual did not master previous developmental tasks, their level or manifestation of hope could look different than someone who progressed through Erik Erikson's developmental stages appropriately. Participants' statements regarding age as a factor in the differing of hope suggest that age does matter from an assessment point of view when looking at the level of hope an individual has, or

in relation to assessing what exactly an individual is hoping for. Due to no previous research in the reviewed literature that examines the relationship between levels of hope and an individual's age, further research will be needed in this area to either support or contradict these findings.

Changes in perspective. Participants discuss the idea that a cancer patient may change his or her perspective; not always hoping for a cure, but rather, hoping for a myriad of other things instead. The differing of what an individual can hope for supports the current state of literature in that Elliott and Olver (2007) discuss that if individuals have hope, they have the ability to consider the possibility of a “future with positive aspects to it” even if it comes down to how they experience their death (p. 144). Similarly, the idea that cancer patients can, at times, either change what they are hoping for or simply start out hoping for something other than a cure is very prevalent throughout this study. Participants' comments on hope support the idea that hope is not a constant factor, and that as time progresses with an individual's illness, the individual's hope may change while still being present. Statements regarding the differing of hope note that it is important to be aware of the idea that hope can fluctuate, and supports the need for the ongoing assessment of hope in cancer patients regardless of age. Throughout the interview process, the dynamics of patients' hope shifting from hope for a cure to things such as having control, being comfortable as death approaches, living long enough to see family members get married or to witness the birth of babies, and having family around when they pass were mentioned by various participants.

The idea of hope and the acceptance of reality being intertwined is discussed by one participant in this study in regards to how hope evolves and is a part of the healing

process. This relationship is also alluded to in the current literature reviewed. For example, Miller (1985) states, “I believe that hope influences the healing response and is necessary to prevent the physical and mental deterioration that come with despair brought on by illness” (p. 23). The way in which one participant in this current study explained cancer patients’ acceptance of reality, in which they reach a point where they are accepting of what is happening, correlates with Miller’s (1985) statement that this change in perspective, and its direct relation to hope, could “prevent the physical and mental deterioration that come with despair brought on by illness” (p. 23). This participant’s comments on this direct relationship suggest that hope can differ based on whether or not a cancer patient has accepted the reality of their situation or if they are in denial of the situation. Overall, the findings of the current study contribute to the knowledge that hope can differ in relation what is hoped for, but further research is needed in the area of a patient’s age and its influence on hope in order to confirm or deny the findings of this study in relation to age.

Faith and Healing

The ability to be at peace. Participants of this study comment on the relationship between faith and/or faith-based services and healing. They spoke to this relationship when asked if they had noticed any relationship between utilizing faith-based services and an individual’s healing process, or whether they see faith-based services being a component of the healing process for cancer patients. Participants articulate both that there is a relationship between these two factors and that they do see faith and/or faith-based services being a component of the healing process for cancer patients.

The findings of this current study in relation to the idea of faith aiding cancer patients' in their ability to be at peace support Dann et al.'s (2005) statement that spirituality delivers "strength, comfort, and hope" to cancer patients (p. 1). Participants of this current research study mirror these ideas in statements articulating the positive relationship between faith and healing in that if cancer patients have a faith background or utilize faith-based services they are more able to find a sense of inner peace and be okay with their cancer journey. Statements provided by the participants contribute to this already present knowledge by adding that either having a faith background or utilizing faith-based services provides cancer patients not only a sense of comfort, but also the ability to be at peace.

The belief that there is something more or better to come. Participants in this current study commented on the idea that cancer patients who have faith and/or utilize faith-based services are able to have the belief that something more or better will come, especially in the sense of going to heaven. Findings of the current study, indicating this belief of something more or better to come, support the literature reviewed. For example, it was found in research conducted by Whitford and Peterson (2008) that people with higher meaning in their life would carry on as they had before their diagnosis "with a positive outlook and hope" (p. 1124). The idea of carrying on "with a positive outlook and hope" (Whitford & Peterson, 2008, p. 1124) is also supported in comments made by participants.

The statements by participants in regard to the impact of faith on healing support the effectiveness of the utilization of faith-based services by cancer patients, whether in providing the sense of being at peace in the moment, or supporting the belief that

something more or better will come after death. A comment by one participant that “having some kind of faith-based person in the picture has typically done a more positive thing than not, and I think it can bring healing” speaks to the overall effectiveness and positive outcomes of cancer patients utilizing faith and/or faith-based services. Another participant comments, “Whether it’s part of the healing process or just a part of the journey I think it’s certainly significant for folks.” These statements suggest the importance of making sure faith-based services are available to patients if it is something they desire, need, or is a part of their everyday life. Another idea that further supports the utilization of faith and/or faith-based services is that if an individual has a strong faith and/or utilizes faith-based services during the time of their illness they are more likely to find peace with their situation and be able to better handle their cancer journey.

Strengths and Limitations

Strengths. The primary strength of this current study is the snowball sampling method used. This sampling method resulted in information being made available to multiple individuals who then either directly identified another participant or contacted further potential participants to inform of them of the study. This snowball sampling method led to the recruitment of all participants, except for two who were initially contacted by the researcher.

A secondary strength of this current study is that qualitative methods were used to capture the experiences of social workers that have worked with cancer patients and/or geriatric populations in medical settings. This method of conducting qualitative interviews allowed participants to speak to their experience, provide specific examples, and provided the opportunity for the researcher to ask follow up questions to elicit more

information from participants. Therefore, the qualitative method used in this current study allowed for participants voices to be captured in detail, which may allow for a new understanding in relation to ways in which the presence of hope can aid in adjustment to a cancer diagnosis or illness, how poor mental health is related to levels of hope among cancer patients, as well as how the absence of hope potentially leads to increased complications throughout treatment and with regard to healing.

Limitations. Aside from the strengths of this study, there are limitations to be noted. Small sample size and recruitment are limitations of this study. Recruitment of a target sample was difficult, and due to the use of a convenience sampling method, the generalizability of the findings is limited; a representative sample was not obtained. In addition, participants of this study did not work specifically with cancer patients in the terminal phase of illness, nor in elderly specific settings, but in more general cancer care settings, which resulted in participant statements being generalized to cancer patients of all ages and all stages of illness. Based on this fact, it is hard to quantify or qualify how much participants knew specifically in relation to elderly cancer patients with terminal cancer.

Implications for Social Work Practice

The findings of this current study suggest implications for social work practice that include the importance of recognizing, fostering and maintaining hope; ensuring ample time to interact with cancer patients; understanding development in relation to age and hope; and understanding the importance of assessing cancer patients' hope. Participants in this current research commented on their awareness that hope can fluctuate with regard to age and type of hope, and the importance of fostering a sense of

hope among cancer patients. Findings from this study support the importance of recognizing, fostering, and maintaining hope in anyone going through a medical journey, especially those coping with cancer. For example, one participant articulates this point when she says,

We should always be relaying a sense of hope. Not that everything's going to go away and everything will be fine, but just letting people know that there are resources and services and treatment options, and even if it gets to that point of needing hospice, that can still be portrayed in a hopeful, supportive way.

Life reviews, or creating acceptance of one's life through examining memories, as discussed in the literature, would be a valuable tool for social workers in terms of fostering and maintaining hope in cancer patients (Johnson, 2007).

Another participant recognizes the importance of fostering hope in individuals, and she also discusses the importance of recognizing an individual's hope in the first place. This participant demonstrates this point when she comments,

I do think it's probably more of the culture of the treatment team, or the culture of the doctors [and] nurses to recognize that hope changes; to recognize that there could always be hope, to facilitate a positive environment, and to always be very honest and open with the patient and their family.

In addition to this recognition of hope being a part of the culture of doctors and nurses, it is also an important part of the culture of social workers, especially those working with cancer patients in medical settings, as indicated by findings of this study.

Aside from recognizing, fostering, and maintaining hope within cancer patients, another implication of this current study is the importance of social workers

understanding the impacts of age and development on hope within cancer patients of all ages. Even if a social worker, who wishes to work with cancer patients, does not intend to work with elderly individuals, the experience of participants in this study indicates that a variety of ages, including the elderly, will be encountered in cancer care. Knowledge of Erikson's developmental theory, *Eight Stages of Man*, as discussed earlier, would be beneficial for social workers who are working with cancer patients of all ages, as how individuals progress through development can impact how they view their current life situation and respond to their cancer. Even broader than Erikson's theory would be the importance of understanding the issues or tasks that accompany old age. For example, elderly individuals may not always be engaged in forward thinking, but may be in a position to reflect back on their life. The desire to reflect back, as previously noted, would make facilitating a life review a useful tool for fostering hope within the elderly. However, if a social worker did not understand the need, or desire, of elderly individuals to reflect back on life, a useful intervention may not be used. It is important for social workers to have knowledge of late life development in order to foster hope within elderly cancer patients, as well as younger cancer patients.

Findings of this study indicate it is important for social workers to recognize the importance of hope, and this can be done through formally assessing for the multiple dynamics embedded within hope during an initial intake. As discussed in the literature review, the Herth Hope Index, which is normed for use with elderly terminally ill patients, is an example of a tool to consider when conducting assessments (Herth, 1992). Using formal assessments of hope would give social workers the ability to identify hope or the absence of it, foster hope, assist in the maintenance of hope, facilitate interventions

to help the patient identify things like everyday miracles, help patients realize their cancer does not define them, and help patients identify other positive things in life that can instill hope. A formal hope assessment would be most beneficial if it happened on a recurring basis throughout the individual's illness in order to account for changing dynamics that can affect the experience and manifestation of hope.

Not only does this current study present assessment implications, but it also illustrates the need for social workers to spend ample time with cancer patients. Patients would benefit if this time with social workers was incorporated into cancer care. In order for social workers to complete life reviews, assess the patients' needs, fully recognize, foster and maintain hope within this population, time is essential. Not only does it take time to complete a thorough and accurate assessment, but social workers need enough time to sit down with a cancer patient and talk with the individual and relay a sense of hope. These conversations, that take time, can help in fostering and maintaining hope within the individual.

Recommendations for Future Research

Aside from social work practice implications, there are three research implications as a result of this current study. One implication would be the need for further research on the topic of the use of hope and faith-based services in healing, specifically in relation to elderly cancer patients. The elderly population is projected to grow greatly in the coming years (Ershler, 2003), and this population will make up a large number of the new cancer diagnoses (news-medical.net, 2012). Based on these two things, knowledge of how elderly individuals with cancer utilize hope and faith-based services in their healing process will be vital, which is why further research in this area is

recommended. This study also suggests the need for further research in the areas of how a cancer patient's mental health (past or present) as well as their age can impact their level of hope.

Recommendations for Future Policy

Considering that ongoing assessment is a pivotal part of social work practice, along with the idea that an individual's level of hope can be variable, it may be beneficial to use a standardized assessment tool to measure and assess hope in hospital or other settings that treat cancer patients. A suggestion for this assessment would be the Herth Hope Index (Herth, 1992). It is recommended that this assessment be incorporated into the policies and procedures of all hospital and medical facilities. This would ensure that one's level of hope, as well as how one's hope is changing, is being acknowledged, identified, and fostered to best serve the individual.

Conclusion

This current study provides the perspectives of hospital or medical social workers in relation to how elderly individuals with terminal cancer, as well as cancer patients in general, utilize hope and faith-based services in their healing process. Overall, participants of the current study indicate that the utilization of hope and faith-based services can positively affect cancer patients of any age, with this also being supported by the literature (Dann et al., 2005; McClement & Chochinov, 2008; Miller, 1985; Whitford & Peterson, 2008). Cancer patients' absence of hope was seen as contributing to refusal of or difficulty with treatment, and patients' mental health seemed to play into an absence of hope and difficult healing process as well. Meanwhile, it is noted that hope can differ and change throughout one's illness, and it is commented that a patient's age can matter,

an ability to accept reality influences hope, and often times cancer patients have a change in perspective and their hope changes in that they may not always be hoping for a cure.

It was revealed through this study that faith could aid patients in their process of coming to a place of peace, and to a place of healing around their cancer diagnoses. It may also illustrate that many cancer patients who have a faith background have an easier time being at peace with their situation or their journey. Also, faith and/or faith-based services play a role in providing cancer patients with the belief that there is something more or better to come, which may provide comfort for cancer patients. Similarly, hope is found to aid in healing in the sense that cancer patients who have hope often times are more able to see the positives in their situation and often bring this sense of hope to the challenges brought forth by their cancer diagnosis.

This research, as well as literature reviewed, highlight and support the need for continued research in the area of the utilization of hope and faith-based services by elderly, late-stage cancer patients. One recommendation for future research is to specifically study terminal cancers across geriatric populations. A second recommendation is to ensure the universal integration a standardized hope assessment tools within settings that work with late-stage elderly cancer patients. Finally, the importance of continual monitoring and fostering of hope in cancer patients of all ages is demonstrated through the findings of this study and is an important element to be incorporated into social work practice globally.

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Appendix A

Interview Questions

1. Can you tell me about your role in working with oncology patients and/or their families?
2. Can you tell me about the patients you see? How would you describe them in general?
3. What are some faith-based services available in your setting?
4. Have you noticed any relationship between utilizing faith-based services, the level of hope a patient has, and their healing process?
 - a. If yes, what have you noticed?
5. How do you identify patients who are “hopeful” versus “hopeless”?
 - a. How do you work with each type?
 - b. How do you see patients’ levels of hope evolve?
6. Do you see hope or faith-based services being a component of the healing process for cancer patients?
 - a. If yes, how is this evident or made manifest?
7. How do you see hope and faith-based services integrated in your setting with oncology patients?
8. Is there anything relevant I haven’t thought to ask that you could add?
9. Do you know someone else that I should talk to? How might I reach them?

Appendix C

Letter of Introduction to Potential Interview Participants

December 12, 2012

Name of Participant

Email Address

Dear Potential Participant:

My name is Kati Thayer and I am currently a student in the Master of Social Work program at St. Catherine University and the University of St. Thomas under the direct supervision of Assistant Professor Kari Fletcher, Ph.D., LICSW. I have contacted you because you are a hospital social worker in the Twin Cities metro area. I would like to invite you to participate in a research study examining how hospital social workers see elderly individuals with terminal cancer utilize hope and faith-based services in their healing process. Faith-based services could include things like prayer, spiritual counseling, or worship services (Cancer Treatment Centers of America, 2012). Hope is something that helps people find meaning, helps maintain well-being, and can help an individual find a sense of purpose or direction (Mattioli, Repinski, and Chappy (2008).

I would like to ask you to participate in a research study because:

1. You are currently or have been a hospital social worker with experience working with elderly cancer patients (preferably in the terminal phase of illness) or:
2. You are currently or have been a hospital/medical social worker with experience working with cancer patients 18 or older or:

3. You are currently or have been a social worker with experience working with the elderly in a medical setting

Your participation in this research study is voluntary; you can stop the interview at any time, and you have one week after the completion of the study to remove yourself and the data you provided from the research process. You will receive a \$10 Target give card in appreciation of your participation. The interview will be audio-taped and used for transcription, but care will be taken to protect and maintain confidentiality of your participation as well as the information you provide. I will utilize your information and present it in a non-identifying way in my final research presentation and paper, which will then be published electronically through St. Catherine University and the University of St. Thomas.

I hope you will agree to participate in my research study, where your knowledge and experience will be greatly appreciated and will contribute to further understanding how elderly individuals with terminal cancer utilize hope and faith based services in their healing process. Included you will find the interview questions to be asked as well as a consent form for you to review prior to your participation in an interview.

Thank you in advance for your time and careful consideration. If you have any questions or concerns about the research project or your participation please contact me via email at tess7439@stthomas.edu.

Sincerely,

Kati Thayer

School of Social Work

St. Catherine University/University of St. Thomas

Appendix D

Consent Form

University of St. Thomas

The Role of Hope and Faith-Based Services as Utilized by Elderly Cancer Patients

[IRB Log # 404611-1]

I am conducting this study to explore hospital social workers' perceptions on how elderly individuals with terminal cancer utilize hope and faith-based services in their healing process. You were selected as a possible participant for this study because you are a hospital social worker who is working or has worked with elderly individuals with terminal cancer, have worked with cancer patients over the age of 18, or have worked with elderly individuals in a medical setting. Please read this form and ask any questions you may have before agreeing to participate in the study.

This study is being conducted by Kati Thayer, a graduate student in social work, who is directly supervised by Kari Fletcher, PhD, LICSW, of the University of St. Thomas and St. Catherine University School of Social Work.

Background Information:

Because the elderly population is projected to significantly contribute to the number of cancer diagnosis, it is important to look at how they cope during the healing process. There is strong evidence not only that hope needs to be studied further, but also specifically hope in relation to the elderly with a terminal cancer diagnosis. Elliott and Olver (2006) state, “many have concluded that hope research is fragmented, imprecise, and episodic” (p. 138). Esbensen and Thomsen (2011) add, “there is a lack of knowledge about elderly people with cancer, especially in relation to those in the advanced stages”

(p. 27). Based on the need for further research, the purpose of this qualitative study will be to examine how hospital social workers view elderly individuals with terminal cancer utilize hope and faith-based services, if at all, in their healing process.

The purpose of this study is to conduct eight to 10 interviews as a part of my clinical research project and is a graduation requirement of the Master in Clinical Social Work program at St. Catherine University and the University of St. Thomas. I will ask you questions about your professional role and experience in relation to working with elderly individuals with terminal cancer.

Procedures:

If you agree to be in this study I will ask you to do the following things: Participate in a one time interview, either in person or via telephone. The interview will be approximately 45 to 60 minutes in length, will include nine questions, and will be audio recorded. You will be given interview questions, a letter of introduction describing the research, and consent form to sign if you agree to participate after reading the letter of introduction. You will receive these forms via email prior to your interview. You may decline to answer any question you are not comfortable answering. Your interview will take place in a private location to be decided on between you and the researcher prior to the time of the interview. The interview will be audio recorded and a research assistant who signed a confidentiality agreement will use the audio recording for transcription purposes. The audio recording of the interview will only be available to the researcher and research assistant. The audio recording will be stored on a secured external hard drive, and will be deleted from the hard drive three years after completion of the research.

The audio recording and transcription information will be deleted from the research assistant's password protected personal computer upon completion of transcription. For the interview process, the researcher will read you the previously provided interview questions, which may be followed by some prompts or further questions depending on your response to the questions. You are able to decline participation or terminate your participation at any time and have one week after completion of the interview to remove the information you provided from the research process.

Risks and Benefits of Being in the Study:

This study poses minimal risk. The study and interview questions may bring up difficult or emotionally charged topics related to working with cancer patients. This could result in mild discomfort. A resource list will be provided after the interview and will list mental health and counseling resources if any information or assistance is needed. There are no direct benefits to participation in this study.

Compensation Provided:

Note: In the event that this research activity results in an injury, treatment will be available, including first aid, emergency treatment and follow-up care as needed.

Payment for any such treatment must be provided by you or your third party payer if any (such as health insurance, Medicare, etc.)

A \$10 Target gift card will be provided as a token of appreciation for participation in the research study. Receipt of this gift card is not contingent on your full participation and/or completion of the study; you can still skip questions or provide varying amounts of information based on your comfort level with any given interview question. If you choose to terminate your participation in the study you will still receive the \$10 gift card.

Confidentiality:

The records of this study will be kept confidential. Information given in your interview will be presented to the public as a part of the researcher's graduation requirement, but care will be taken to protect confidentiality and no identifying information will be provided either in the oral presentation or written report.

After completing each interview, the audio will be reviewed, and the entire interview will be transcribed by a research assistant who signed a transcriber confidentiality agreement form. After transcription, the data will be stored on a secured external hard drive, and will be deleted from the hard drive three years after completion of the research. The audio recording and transcription information will be deleted from the research assistant's password protected personal computer upon completion of transcription. Each participant's signed consent form and any written notes will be stored in a locked file cabinet in the researcher's home. These consent forms will be shredded at the same time the transcription material is deleted from the researcher's computer hard drive.

Each interview recording, the following transcription, and each participant's signed consent form will be destroyed on or before May 1, 2016. The audio recording and transcription information will be deleted from the research assistant's password protected personal computer upon completion of transcription.

Care will be taken to ensure confidentiality by limiting viewing of the data to the researcher, their research advisor, a research assistant who signed a confidentiality agreement form, and the Institutional Review Board.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with any cooperating agencies or institutions or the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until the date/time specified in the study. You are also free to skip that may be asked. Should you decide to withdraw, data collected about you will not be used in the study.

Contacts and Questions:

My name is **Kati Thayer** and you can ask me any questions you may have now or before the interview takes place. If you have questions later, you may contact me at tess7439@stthomas.edu. You may also contact **Kari Fletcher**, PhD, LICSW, my research advisor, at 651-962-5807, or the University of St. Thomas Institutional Review Board at 651-962-5341 if you have any questions or concerns.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction and I am at least 18 years old. I consent to participate in this study.

Signature of Study Participant	Date

Print Name of Study Participant	Date

Signature of Researcher	Date

Appendix E

Mental Health and Information Resources

Interprofessional Center for Counseling & Legal Services (651-962-4820)

The Interprofessional Center for Counseling & Legal Services is comprised of services provided through the University of St. Thomas. Services are provided by students of Professional Psychology, Social Work, or Law. Psychological assessments and evaluations are provided at this location, as well as individual counseling and psychoeducation, all provided by students pursuing either a doctoral or master's level degree. All services are free of charge and are located at 30 S. 10th Street Minneapolis, MN 55403.

Crisis Connection (Minnesota Crisis Line: 612-379-6363, or 1-866-379-6363)

Crisis Connection provides telephone counseling services and support 24 hours a day, 365 days a year. Crisis Connection specialized in counseling, interventions, and can also make referrals.

Rum River Counseling, Inc.

Rum River Counseling Center provides free, anonymous, online assessments for conditions such as Depression, Generalized Anxiety, Alcohol Abuse, Bipolar Disorder, Eating Disorders, and Post Traumatic Stress Disorder. These are simply a screening to be used to assess if there is a need for further services. These screenings are not meant to be diagnostic and treatment recommendations are not provided, but if you are concerned or feel at risk for one of the above stated conditions, you may seek services at one of their six offices:

- Molly Professional Center- 2705 Bunker Lake Blvd. NW, Suite 100-
Andover,
MN 55304- 763-482-9598
- 11870 Ulysses St. NE, Suite 200 - Blaine, MN 55434- 763-482-9598
- 4600 Oak Grove Parkway- Brooklyn Park, MN 55443- 763-482-9598
- Grand Hill Professional Building- 333 Grand Ave, Suite 103- St. Paul,
MN 55102-763-482-9598
- 15832 Venture Lane- Eden Prairie, MN- 55344- 763-482-9598 or 952-270-
3822
- Annapolis Office Park- 3370 Annapolis Lane N, Suite C -Plymouth,
MN 55447-763-482-9598 or 952-270-3822

Urgent Care for Adult Mental Health- 402 University Avenue East, Saint Paul, MN
55130

Urgent Care for Adult Mental Health provides an array of services from mobile crisis teams that go out to desired locations, mental health crisis assessment, peer support, education, and referrals. A 24/7 crisis line is also available and can be reached at: 651-266-7900. Walk-ins are welcome at this site and no appointment is necessary. The sites hours are: **Monday – Friday** 8:00 am – 9:00 pm **Saturday - Sunday** 11:00 am - 3:00 pm