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Cancer Patients' Spiritual Well-Being, Religious Coping, and Comfort in Communicating with Physicians

Cheryl Boettger
Walden University

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Cheryl Anne Boettger

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Walden University
2024

Abstract

Cancer Patients' Spiritual Well-Being, Religious Coping, and Comfort in
Communicating with Physicians

by

Cheryl Anne Boettger

MS, Walden University, 2012

BS, University of Phoenix, 2009

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Psychology

Walden University

May 2024

Abstract

Terminal cancer patients with unmet spiritual needs are more likely to suffer from depression, anxiety, and an overall decrease in the quality of their physical, mental, and spiritual health. Even though the incidence of cancer continues to increase, with better treatment, patients are surviving longer. There is a known connection between spiritual, and physical well-being, but research has indicated that this connection is sometimes overlooked in certain populations. In this phenomenological qualitative study, the participants' lived experiences communicating with their physician about spirituality while in treatment for cancer were examined. The biopsychosocial-spiritual model was used to explore the lived experiences of nine participants who were cancer survivors communicating with their physician about spirituality while in treatment for cancer. Data from the interviews were analyzed through coding and the development of themes. The results indicated a broad spectrum of definitions of spirituality, with the participants using the terms religion and spirituality interchangeably. The participants confirmed the perceived separation between medicine and spirituality, although most patients indicated they would have benefited from some spiritual conversation initiated by the physician. This study may lead to positive social change by improving physicians' understanding of what their patients need, thus improving patient care by potentially improving communication between patients and physicians, decreasing anxiety and depression as well as improving spiritual well-being for patients.

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Dedication

This is dedicated to my amazing husband, Deane Boettger. Thank you for all of your support and encouragement. I could not have done this without you!

I would also like to thank my mother-in-law, Sylvia Maloney. Next to Deane, you have been my biggest cheerleader and have always encouraged me. Thank you to Linda Hacker, you are an amazing woman I am lucky to have in my life!

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Chapter 1: Introduction to the Study

Many terminally ill patients do not communicate their spiritual or religious needs with their physicians (Best et al., 2016). As treatments and medical technologies improve, patients are surviving longer with potentially terminal illnesses (Miller et al., 2019). However, many patients report feeling that their spiritual needs are not being met (Best et al., 2016). Although a recent Gallup Poll showed roughly 90% of Americans believe in God (Hrynowski, 2022), many physicians are hesitant to approach their patients regarding spiritual concerns (Best et al., 2016a). This can limit patient support systems, lower spiritual well-being, increase depression, lower the immune response, and further decrease patient quality of life (King et al., 2013). Research has indicated that spirituality may play a significant role in supporting oncology patients, which could impact patient outcomes (Ellington et al., 2017). Receiving the desired amount of spiritual care during hospitalization could significantly reduce the risk of depression and improve the patient's spiritual well-being (Pearce et al., 2012). Cancer patients would like to include their doctors in the spiritual aspect of their care for a more holistic approach; however, spiritual conversations are infrequent due to insufficient training and knowledge, with the result that many individuals feel their spiritual needs were not met (Best et al., 2016b).

In this chapter, I provide the problem statement and research gap, the purpose and nature of the study, the research questions, and the conceptual base. Operational terms are defined. I also discuss the assumptions, limitations, scope and delimitations, and significance of this study.

Background

Identifying those patients with unmet religious or spiritual needs and providing them with intervention and increased support could reduce depression and increase quality of life (King et al., 2013). Best et al. (2015) examined 54 studies that included 12,327 patients and found significant communication gaps in what patients expected from their physicians compared to what they received. Best et al. discovered four themes: patients want holistic care, patients feel disempowered, patients would like more spiritual guidance, and the connection between spirituality and healing. Many patients feel vulnerable in the medical setting and are not comfortable initiating conversations with their doctors regarding spirituality (Best et al., 2015). Patients would like to feel their physicians know them on a deeper level than merely physical and believe that a level of respect and trust needs to be established for that communication to be effective (Best et al., 2015). When this element of intimacy is missing, patients report disappointment (Best et al., 2015). Best et al. suggested that more research should be conducted to help understand and define religious or spiritual struggles to help physicians better understand when communication is lacking.

Even though spirituality has been acknowledged as playing a critical role for patients, research is not as robust on how social support can increase spiritual well-being as it could be (Meluch, 2018). Meluch (2018) conducted semistructured, in-depth interviews with three men and 28 women diagnosed with cancer who regularly used the Cancer Wellness Center. While there were inherent limitations, such as the male to female ratio, three themes emerged from the study: cancer patients identified with the

ability to have spiritual communication connected to their perceived meaning of their illness, their perceived ability to connect with others through the shared experience of cancer, and the perception of centeredness through this spiritual communication.

Meluch's findings support the possibility that a cancer diagnosis refocuses the patient's spiritual concerns and their need for increased communication opportunities and validation. Patients might perceive an improvement in their quality of life based on an increase in spiritual communication and validation from their health care providers (Meluch, 2018).

Sirilla and Overcash (2013) studied the quality of life of 159 cancer patients treated with hematopoietic stem cell transplant for varying stages of leukemia and lymphoma in relationship to their supportive care resources. They found an overall decrease in quality of life in all subjects after 30 days and that most patients relied on their physicians and nurses for the most information about support services. They recommended future research to include patient perceptions of available spiritual resources (Sirilla & Overcash, 2013).

Determined to maintain scientific purity, many practitioners of the Western medical system either distance themselves from or deny altogether the spiritual side of humanity (Dein et al., 2010). Many researchers have failed to design and conduct empirical research specifically regarding topics concerning spirituality that have any theoretical basis. Other researchers have diminished the validity of their studies by using vague definitions of the terms associated with the studies, such as religiosity, spirituality, mind, soul, faith, and God (Johnstone et al., 2009). It is possible that because of some of

these limitations, in addition to the perceived privacy of the topic, that much of the academic and scientific community disregards spiritual concerns altogether. Another possible confounding influence could be patients' reluctance to discuss spiritual or religious issues because they feel it is too personal or private. Culture can further complicate the physician's responsiveness. For some patients there is a blur between the distinction of culture and religion that further complicates physicians' responses (e.g., being Jewish can be a matter of religion or a matter of heritage; Borneman et al., 2013).

In an effort not to offend, many physicians opt to ignore spirituality altogether. For example, Pearce et al. (2012) found that 42 out of 150 inpatient oncology patients reported receiving less spiritual care than they wanted from the hospital, chaplain, and religious community. This lack of spiritual care increased the incidence of depression and reduced overall physical health in that sample. Rosequist et al. (2012) reported an increase in positive patient coping when patient optimism and active acceptance were enhanced with physician intervention. However, Ramondetta et al. (2013) studied 635 physicians and found a significant number did not feel they were qualified to discuss spirituality with their patients.

Problem Statement

Spiritual health, or spiritual well-being, is defined as an individual's worldview in combination with their individual sense of purpose and ethical guidelines that culminate in personal fulfillment, including connectedness to others and "a higher power or larger reality" (Hawks, 1994, p. 3). Spirituality refers to the way individuals find meaning in

their lives and how they “experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Puchalski et al., 2009, p. 887).

Previous research has found a connection between spiritual well-being and physical well-being; however, some populations appear to go unnoticed perhaps due to geographics (Best et al., 2015; King et al., 2013; Rosequist et al., 2012). In a meta-analysis of 54 studies, Best et al. (2015) found there were substantial disparities from what patients expected and what they received in terms of communication. This gap was explored in the current study. By physicians increasing their comfort with communication regarding spiritual issues and incorporating more holistic care, cancer patients could have a decreased incidence of depression and an increase in their overall spiritual and physical well-being. Decreasing mental anguish could improve patients’ physical well-being, which could positively impact their quality of life.

Purpose of the Study

The purpose of this qualitative phenomenological study was to examine the lived experience cancer survivors had of communicating with their physicians about spirituality. Not only does the incidence of cancer continue to increase, but with better treatment, patients are surviving longer (Miller, 2019). There is a known connection between spiritual well-being and physical well-being, but research has indicated this connection is sometimes overlooked in certain populations (Best et al., 2015; King et al., 2013; Rosequist et al., 2012). To address this gap in the literature, I employed a qualitative phenomenological study to explore how individuals in this population perceive their spiritual needs and its impact on their quality of life.

Nature of the Study

A qualitative phenomenological study design was an appropriate approach for this study. The phenomenon explored was the spiritual communication experiences of cancer survivors during their treatment. In this study, I identified one concept to explore, from individuals who lived the experience, using a conceptual framework to find the essence of the experience (see Creswell, 2016).

Research Question

A key component of a qualitative phenomenological study is answering the question of how the target population is experiencing the phenomenon (Creswell, 2016), Using that overarching question as a guide, I developed the following research question: What are the lived experiences of patients communicating with the physician about spirituality while in treatment for cancer?

Conceptual Framework

The conceptual framework for this study was the biopsychosocial-spiritual model (see Sulmasy, 2002). Sulmasy (2002) developed this model to help understand the relationship between the mind, spirit, and body in relation to factors, such as culture, socio-economic status, support networks, and education. Each of these aspects of the mind-spirit-body impact the others, so when illness disrupts one aspect, the others become unbalanced, causing the individual distress (Sulmasy, 2002). By developing the biopsychosocial-spiritual model, Sulmasy suggested that if all aspects of the individual were treated, balance could be restored, improving the quality of life, especially in terminal patients.

The biopsychosocial-spiritual model accounts for the biological components that impact cancer, including, but not limited to, genetics, temperament, and previous health history (Matrenitsky, 2021). Prolonged psychological stress contributes to depression, helplessness, and hopelessness (Matrenitsky, 2021). When physicians incorporated the biopsychosocial-spiritual model into cancer patients' treatment, healing was increased and expedited (Matrenitsky, 2021).

The biopsychosocial-spiritual model was an appropriate framework for this study because of the holistic concept that supports people as complex beings with multifaceted needs. According to Sulmasy (2002), this framework was designed to help health care providers better consider a holistic approach to treating terminal patients. By utilizing this framework for the current study, I was able to take all aspects of the individuals into consideration (see Sulmasy, 2002).

Definition of Terms

Quality of life: The World Health Organization (1997) defined quality of life as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (p. 3).

Religion: “The search for significance that occurs within the context of established institutions that are designed to facilitate spirituality” (Pargament et al., 2013, p. 15)

Religious/spiritual (R/S) struggle: “Strain, tension, and conflict about sacred matters with the supernatural, with other people, and within oneself” (Abu-Raiya et al., 2015, p. 566).

Religiosity or religiousness: Also referred to as, “personal and institutional beliefs along with institutional practices, such as attending worship services, usually reflecting conformity and adherence to a basic set of tenets and proscribed behaviors” (Baetz et al., 2006, p. 655).

Spiritual well-being or spiritual health: A “high level of faith, hope, and commitment in relation to a well-defined worldview or belief system that provides a sense of meaning and purpose to existence in general, and that offers an ethical path to personal fulfillment which includes connectedness to self, others and a higher power or larger reality” (Hawks, 1994, p. 3).

Spirituality: “The aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Puchalski et al., 2009, p. 887).

Assumptions

The assumptions inherent to this study were that all participants answered the interview questions honestly and to the best of their ability, that all participants had a Stage 2 or higher cancer diagnosis, and that there was an adequate representation from diverse demographics. I also assumed the duration of the study was adequate, and the technology used was accessible to the participants.

Limitations

There were a number of limitations to this study. One limitation was that there was no way to predict the participants' perceptions of their lived experiences. Another was that this study was voluntary so there may have been some bias on the part of the participants, reducing external validity. The participants had been terminally ill and may have suffered from a sudden health decline or death, which was also a limitation. Finally, the participants were limited to only those who were English speaking.

Scope and Delimitations

The scope of this study was centered on cancer patients who had survived and who were willing and capable of completing interviews regarding their perceived satisfaction and ability to communicate with their primary physician concerning spiritual well-being and spirituality. Initially, I recruited participants on social media, such as Facebook, to increase the potential diversity of the individuals. However, most participants were recruited through the snowball effect.

Significance of the Study

In this study, I examined the lived experiences of patients communicating with the physician about spirituality while in treatment for cancer. The results of this study may lead to positive social change by increasing cancer patients' quality of life and the quality of life of their families and support groups as well as improving provider care options. The results could also improve physicians' understanding of what their patients need, improving patient care.

Summary and Transition

In this chapter, I highlighted the limitations of previous studies researching religious or spiritual communication between the cancer patient and their physician. When a patient perceives a deficiency in religious or spiritual communication, it can lead to a diminished quality of life for the patient and their family (Sirilla & Overcash, 2013). I also provided a brief overview of the purpose of this study, the nature of the study, the research question, and the theoretical basis. The gap in the literature, potential for social change, and the significance of the study were also discussed. Finally, I defined terms used in the study and addressed the limitations and scope of this research.

In Chapter 2, I will provide a review of the literature that was used to understand this issue and show the gap in the literature on this topic. In Chapter 2, the conceptual framework for this study will also be discussed in greater detail.

Chapter 2: Literature Review

Many terminally ill patients do not communicate their spiritual or religious needs with their physicians. As treatments and medical technologies improve, patients are surviving longer with potentially terminal illnesses; however, many patients feel that their spiritual needs are not being met (Miller, 2019). Although 90% of Americans believe in God (Pew Research Center, 2014), many physicians are hesitant to approach their patients regarding spiritual concerns (U.S. Department of Health and Human Services, 2009). This can limit patient support systems, lower spiritual well-being, increase depression, reduce the immune response, and further decrease patient quality of life (King et al., 2013).

The American Cancer Society (ACS; 2024) predicted that nearly 2 million new cases of cancer will be diagnosed in the United States in 2024 and that 611,720 cancer patients will die. In the United States alone, expenditures for cancer reached more than \$208.9 billion in 2020 (National Cancer Institute, 2024). Worldwide, cancer is a leading cause of death, killing more than 10 million people each year (National Cancer Institute, 2024). As grim as these numbers may be, improvements in treatment mean an ever-rising number of those diagnosed will survive longer and longer. The ACS estimated the 5-year survival rate of some of the more common types of cancer, such as breast and prostate cancer, at 90% to 99% if diagnosed during the early stages. Unfortunately, other types of cancer, such as pancreatic and lung cancer, currently have between 8% to 18% 5-year survival rates (ACS, 2024). This difference in survival percentages (i.e., 8% to 99%) could lead to confusion and increased stress in the diagnosed. Obviously, faster diagnosis

and treatment improves these percentages, but the increased survival rates also add some complicating factors for the cancer patients and their support systems, including more lengthy and complicated treatments and procedures, increased stress from prolonged illness, financial burden, and increased time for soul-searching and religious or spiritual struggle (Miller, 2019).

Although the 1946 World Health Organization's definition of health included physical, mental, and social well-being, the integration of these three factors has long been resisted (Chidarikire, 2012). For many years, there has been a dichotomy in health care between the physical aspect of health and the spiritual aspect (Dein et al., 2010). Because of this separation, many health care providers have taken the road of least resistance and avoided the topic all together. There are a number of reasons why physicians feel reluctant to address their patient's spiritual needs. Many feel it is not their domain, others do not feel qualified to address this need, and still others do not believe in the spiritual aspect of health (Ramondetta et al., 2013).

Researchers are compiling a growing body of evidence on the connection between emotional, spiritual, and physical health. Increasing spiritual health directly correlates to increasing overall quality of life (King et al., 2013). Therefore, it is in the patient's best interest if the support system includes spiritual and emotional care as well as physical. Cancer impacts not only those diagnosed, but everyone in their lives. The higher quality of life cancer patients experience, the higher quality of life their support systems enjoy (Krug et al., 2016). Once diagnosed, patients look to their physician to take the lead in their total health care, and whether they are qualified or not, physicians often play a vital

role in the dissemination of information regarding all resources available for all health aspects of the cancer patient.

The purpose of this literature review was to examine previous studies conducted on patient satisfaction regarding their spiritual care during cancer treatment and physicians' attitudes on patient spiritual care. I used the biopsychosocial-spiritual model as a conceptual framework in the study. The misuse and misunderstanding of consistent, reliable definitions for some of the terms, such as spirituality and spiritual struggle, which compound the problem, was also explored. This literature review was focused on research outcomes, with the intent that the synthesis and analysis of results would help generate a better understanding of research gaps, thereby helping to justify this study. Most of the literature reviewed was from quantitative or mixed-methods research with limited open-ended questions.

Literature Search Strategy

The literature search parameters included peer-reviewed, scholarly articles that were primarily published less than 10 years ago with some exceptions, including an original article by Engel (1977). The publication date parameters were 2007 to 2024. I accessed the following databases through the Walden University Library: Academic Search Complete, Expanded Academic ASAP, ProQuest Central, Science Direct, EBSCOhost, and ProQuest Central. The latter two databases were the most frequently used. Google Scholar was also searched for articles not available through the Walden University Library holdings. Key search words included: *spirituality*, *biopsychosocial-*

spiritual, Engel, religion, religiosity, cancer, defining, physician-patient communication, quality of life, spiritual well-being, and religious/spiritual struggle.

Conceptual Framework

Since the 1600s, Western physicians have made the claim that their chief aim is to treat “the whole person;” however, many times they have fallen far short. In an effort to rely solely on empirical evidence and the scientific method, aspects of humanity have been neglected and cultural, social, and spiritual concerns were not addressed (Engel 1977). Even in psychiatry, the biomedical model was adhered to (Engel, 1977).

During the middle of the 20th century, psychology was reaching a critical turning point. Until that point, psychiatrists, psychologists, and physicians had for the most part, adhered to strict disciplinary lines: Physicians dealt with the body, and psychiatrists and psychologists dealt with behavior (Engle 1977). The prevailing belief at the time was that never the twain shall meet (Engel, 1977). But more and more evidence was surfacing that was making the body-mind-spirit connection impossible to deny. According to Engel (1977), there was still a large school of thought within the medical community that believed “mental illness is a myth” (p. 129). Those working in mental health, desperate to maintain respectability and credibility, did everything they could to work within the confines of the biomedical model (Engel, 1977). Remnants of this mindset are still visible in both the medical field and the mental health field today. Many professionals opted out of the argument all together – yet there needed to be a bridge.

In the mid-1970s, Engel (1977), a professor in psychiatry and medicine at the University of Rochester Medical Center who was concerned about whole patient care,

began to build that bridge. Engel (1977) saw the exclusion of social and psychological concepts from the definition of disease as severely limiting. By incorporating elements of the biomedical model with a psycho-social aspect, Engel attempted to empower both the care provider and the patient. Engel believed the social context of the patient and their condition was an important aspect of understanding the disease process. Engel's biopsychosocial model (BSP) attempted to incorporate a holistic picture of the patient's condition, their socio-economic, cultural, and psychological experiences, into overall health and disease (Hatala, 2013).

Even though it was officially endorsed by the American Psychiatric Association and the American Board for Psychiatry and Neurology, as Hatala (2013) pointed out, there have been several points of contention regarding the BPS model. A surprising limitation is the very fact that most people have a higher belief system, and the BPS model does not address the impact of faith on mental or physical health (Hatala, 2013). Another criticism was the vagueness of the definitions of spirituality, of physical health, and of mental illness that the BPS model uses (Sulmasy, 2002). Because of this vagueness, there is a possibility that patients will be limited in care options or denied altogether because of the interpretation by government agencies or insurance companies. A further limitation of the BPS model is the lack of scientific methodology; very limited empirical evidence supporting the model is available (Hatala, 2013). Unlike other models and theories, such as the theory of evolution, contenders have asserted there is no clear scientific method utilized in the BPS model, and there is no clear lineage between claims and outcome.

The biopsychosocial-spiritual model is an extension of Engel's original 1977 model and was developed as a framework to help understand the relationship between the mind, spirit, and body (Sulmasy, 2002). The inclusion of the concept of spirituality provides a basis for the association between the physical and the nonphysical. It is possible that this theoretical lens could provide a better understanding of the body-spirit-mind connection and help bridge the gaps that have been heretofore impeding not only research but also health. Sulmasy (2002) contended that people are multidimensional beings that need to be treated on all levels to maximize their experience. According to Sulmasy:

A human person is a being in relationship—biologically, psychologically, socially, and transcendentally. Illness disrupts all of the dimensions of a relationship that constitute the patient as a human person, and therefore only a biopsychosocial–spiritual model can provide a foundation for treating patients holistically. (Hatala, 2013, p. 268)

According to Anandarajah (2008), there are very few models that provide a theoretical framework to help physicians include spirituality in whole-person care, specifically towards end-of-life care. Attempts at expanding the BPS-S model to include the effects of religion on health and links between mind and spirit have been met with limited success (Anandarajah, 2008). The single largest obstacle to overcome is the lack of a universally accepted definition of spirituality.

Rego and Nunes (2016) supported the inclusion of spirituality as a foundation for overall health. The BPS-S model “is essential to address the patient in its totality” (Rego

& Nunes, 2016, p. 1). Despite some potential limitations, the BPS-S model provides one of the most comprehensive perspectives relevant to the current study.

Literature Review Related to Key Variables and Concepts

There is an argument that health is as poorly defined as spirituality. Since 1946, the World Health Organization has defined health as “physical, mental, and social well-being, not merely the absence of disease” (Chidarikire, 2012, p. 298). As dictated by the Joint Commission on Accreditation of Healthcare Organizations, the Association of American Medical Colleges, and the World Health Organization, spirituality has been added as part of the education of those in the medical profession (Anandarajah, 2008). Despite some of these efforts, there are still serious obstacles to overcome, such as the identification of adequate definitions, answering concerns about personal and ethical boundaries, and addressing cultural differences.

The Archstone Foundation sponsored a consensus conference in 2009 to create a universally accepted definition of spirituality, and members of the consensus drafted the following definition:

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred (Puchalski et al., 2009, p. 887).

However, despite these efforts, this definition is not widely accepted or recognized.

Spirituality has been more recently defined as “That personal function which relates life’s meaning to transpersonal reality” (Kaur, 2013, p. 944). Definitions such as this present a

problem when trying to determine the average layperson's level of spirituality. Many people claim to understand the difference between religion (and religiosity) and spirituality. Defining religiosity has proven fairly straight forward, with the widely accepted, broad definition being pertaining to an organized religion or belief system relating to a higher being or beings (Speed, 2013). Unfortunately, putting a definition of spirituality into succinct words has proven to be a difficult task. Many current attempts, such as "transpersonal reality," need footnotes and more definitions, which creates a daunting undertaking for test and survey makers. Like the early measures of IQ, items often reflect concepts that have no bearing on the actual topic. For example, many measures of spirituality have items that deal with social issues, such as honesty and social judgment (Speed, 2013). This raises the question that the measure may not be valid.

An additional problem is that most research addresses spirituality and religion together, which automatically excludes individuals who may consider themselves spiritual but do not identify with a religious affiliation (Rego & Nunes, 2016). Rego and Nunes (2016) defined religion as "an outward expression" of a belief system or spiritual practice while spirituality is a "journey of self-discovery" in search for "the sacred" (p. 2). This broad definition of spirituality makes testing very difficult since each individual could have a different journey and value different concepts as sacred. Rego and Nunes pointed out that many individuals seek out religion as a means to find social and cultural identity and not necessarily as an extension of a spiritual view.

The term R/S struggle also defies common definition. According to one definition, R/S struggle is "strain, tension, and conflict about sacred matters with the

supernatural, with other people, and within oneself' (Abu-Raiya et al., 2015, p. 566). But this definition is not universally accepted and is not necessarily easily understood. Other definitions of R/S struggle specifically discuss demons, possession, and afterlife (Abu-Raiya et al., 2015).

Another aspect of spirituality that will need better definition is that of surrender, in which the patient releases the feeling of control. According to Rosequist et al. (2012), surrender is the spiritual counterpart of active acceptance. In a qualitative study of 23 breast cancer patients using psycho-spiritual integrative therapy (PSIT) to increase their feeling of surrender, the results were uniformly positive with patients reporting that spirituality facilitated surrender. These findings indicate that PSIT could potentially be used to help increase meeting spiritual needs. Limitations of their study include a small study size and the possible lack of truthfulness based on the qualitative design. Rosequist et al. acknowledged that more research needs to be applied to a more diverse population to confirm their preliminary findings on PSIT and its potential for meeting spiritual needs.

Importance of Spiritual Care

Since the inception of the scientific method, psychologists have struggled with the conflict between the reduction of the human to a biological entity and the risk of criticism for not maintaining empirical standards, which has led to gaps in the understanding of the connection between the body, spirit, and mind. Recent research has highlighted this connection and led to a need for further research (Hatala, 2013). According to Meluch

(2018), spirituality impacts the perception of wellness and directs how physicians and their patients communicate.

Higher levels of spirituality correspond to higher levels of physical health, shorter recovery periods, and better mental health (Hatala, 2013). Research in the 1990s indicated a connection between the immune system and spirituality, resulting in improved health (Hatala, 2013). Routine spiritual care has a proven positive impact on patient outcomes (King et al., 2013), but there is still significant resistance among physicians to be a part of their patient's spiritual care (Best et al., 2016). Under normal circumstances, researchers have found that patients are not looking for their physicians to be spiritual advisors but instead feel that their physicians will have a better understanding of the whole patient if inquiries and conversations regarding spirituality take place. Patients do expect their physicians to be able to refer them to appropriate alternatives, such as chaplains, if a spiritual need does exist (Best et al., 2016).

Using a qualitative, semistructured interview Best et al. (2016) explored contributing factors underlying physician resistance to communication regarding spirituality with their patients. Study participants were physicians currently treating advanced, stage four cancer patients from the Medical Oncology Group of Australia and the Australia and New Zealand Society of Palliative Medicine. Twenty-three physicians were interviewed. The interviews were taped and then coded. Data were synthesized into groups and refined into themes. Five major themes were identified: "(1) confusing spirituality with religion; (2) peer pressure; (3) personal spirituality; (4) institutional factors; and (5) historical factors." (Best et al., 2016, p. 3).

In the Best et al. (2016) study participants hesitated to discuss spirituality stating they worried that patients would confuse religion and spirituality. But the authors found that several participants also confused religion and spirituality, citing negative past experiences and guilt associated with those belief systems or organizations. One doctor stated feeling hesitation discussing spirituality with patients because of a fear of the stigma associated with proselytizing.

Discussions regarding faith, religion, and spirituality have traditionally been banned from formal medicine, so participants cited feeling hesitant having these discussions among peers. Many of those interviewed used the word “uncomfortable” to describe the idea of spiritual conversations among peers (Best et al., 2016, p. 5). Several participants stated they felt disapproval from peers regarding issues of faith and worried they were “being inappropriate” (Best et al., 2016, p. 5).

Even though 18 of those interviewed rated spirituality as “very important” to them, and the other five rated it as “moderately important”, an overriding theme Best et al. (2016) found was the potentially conflicting role physicians felt between being evangelical or professional. While some felt that having a deep spiritual base gave them the ability to be open-minded to their patient’s views, “all were conscious of the need to avoid proselytizing without invitation” (Best et al., 2016, p. 6). Some participants stated avoiding the issue altogether for fear of appearing to push their personal agenda.

The structure of the hospital or care-giving institution plays a role the physician’s willingness to discuss spirituality. Best et al. (2016) found that the absence of chaplains in secular institutions increased the probability and acceptability for physicians to display

overtly spiritual behavior, such as praying with their patients. Physicians also reported less hesitation in these situations, stating it felt less like a conflict of interest if a chaplain was not there.

While nearly all 23 physicians surveyed were conscious of the importance of spirituality, Best et al. (2016) found the traditional separation between science and spirituality hard for participants to overcome. One participant stated that the spirit was not something that could be measured with functional magnetic resonance imaging (fMRI), so it is still considered taboo. According to one interviewee “I certainly don’t think we understand the connections between the mind and the body and the spirit in our understanding of a human being. And so I don’t know that we know how to diagnose a broken spirit” (Best et al., 2016, p. 7). Even though most participants in this study reported never actually encountering opposition to spiritual discussions, most felt these discussions were “unexpected” (Best et al., 2016, p. 8).

Best et al. (2016) found an increase in the inclusion of the BPS-S model into empirical medical teachings which has not yet been reflected in the real-world settings. One of the limitations of qualitative interviews would be the small sample size that may not reflect larger populations. However, the need for an attitudinal shift regarding spirituality is a recurring theme in research.

Ramondetta et al. (2013) surveyed 271 physicians from 41 countries regarding their beliefs about their role in discussing and directing their patients’ spiritual care. Participants were recruited from the Multinational Association of Supportive Care

in Cancer and completed on online survey that consisted of 19 close-ended questions. Demographic information was also collected.

One of the survey questions had the respondents define spiritual care by selecting their top two choices from six possible definitions. Most selected spiritual care being defined as “offering emotional support” (49.8%) and “alleviating spiritual/existential pain” (42.4%; Ramondetta et al., 2013, p. 2993). Of the six possible answers, it is possible that none adequately defined spiritual care for these practitioners. The other choices consisted of:

- Helping patients’ illness narrative and life review (10.3 %)
- Helping patients examine and reconstruct their spiritual beliefs answering specific spiritual concerns (17.7 %)
- Offering spiritual practices such as prayer (8.5 %)
- Helping patients find meaning in life through various therapies (0%; Ramondetta et al., 2013, p. 2996).

Respondents were also asked to select spiritual practices they would use with their patients. The question was: “If you were to use spiritual practices which ones would you choose to use? (check all that apply)” The choices were: “Dignity Therapy 27.7%, Logo [sic] Therapy 8.5%, Healing Touch 24.4%, Yoga Therapy 26.9 %, Art Therapy 29.5%, Music Therapy 42.4%, Other 15.5%, and None 13.3%” (Ramondetta et al., 2013, p. 2997). The vagueness of the question-and-answer selection presents a potential problem that could be easily compounded by language and cultural barriers.

Ramondetta et al. (2013) found that 33.6% of the respondents felt they never provided adequate spiritual support to their patients; 26.2% felt they were incapable of providing spiritual support; 12.2% did not feel it was part of their role to provide patients with spiritual support. Overwhelmingly, the respondents reported a lack of definitions to be a hindrance in determining which patients even wanted spiritual support.

This study was potentially limited by bias in the selection of the participants, since they were all members of the Multinational Association of Supportive Care in Cancer. Language barriers were another potential limitation since the respondents spanned 41 countries. Ramondetta et al. (2013) acknowledged a lack of clear definition of spirituality and believed some respondents confused “spirituality” with “religious” (p. 2996). These researchers found that despite limited attempts at a concise definition of spirituality many physicians still have a very vague and ambiguous understanding of the concept and how to discuss it with patients. Cultural and social interpretations regarding already vague definitions presented yet another problem.

Data interpretation could be skewed since this study was not limited to physicians, but also included others in health care such as nurses and dentists. While Ramondetta et al. (2013) found a majority of the respondents considered themselves spiritual, most agreed they did not have sufficient training to even identify those needs in their patients. Ramondetta et al. believed that lack of data from polytheistic, non-Westernized communities to be a gap since most current research focuses on narrow cancer patient populations. Ramondetta et al. recommended further studies with more diverse populations. They also suggested more training among health care professionals

is needed to better “assess and attend to their patients’ spiritual needs” (Ramondetta et al, 2013, p. 2996).

Pearce et al. (2012) recruited 150 participants diagnosed with Stage III or above who were given a year or less to live. They used the Functional Assessment of Cancer Therapy-General (FACT-G; Cella, et al., 1993), the Center for Epidemiological Studies Depression (CES-D) Symptoms Index Short Form (Radloff, 1977), the Functional Assessment of Chronic Illness Therapy—Spiritual Well-being (FACITSp; Peterman et al., 2002), and developed an 11 item spiritual needs and spiritual care survey to determine if these patient’s spiritual needs were met and if not, to measure if there was any detrimental impact on quality of life and or spiritual well-being. These researchers found a significant minority (28%), felt their spiritual needs were not being met and reported higher rates of depression. They found that 91% reported having spiritual needs and 68% reported having at least a portion of these spiritual needs met. However, Pearce et al. speculated on several reasons for these numbers. First, according to Pearce et al. spiritual care is more easily provided on an inpatient basis. Second, this study was conducted in the extreme southern part of the United States in an area known to be more religious overall. Finally, spiritual needs appear to amplify as the cancer patient approaches the final stages of the disease.

One of the more important findings this study provided was that the majority of patients preferred physician initiation to spiritual conversations. Pearce et al. (2012) also found that even when the patient did not report unmet spiritual needs, if they received

nothing more than a polite inquiry regarding spiritual needs from their physician, they reported lowered incidence of depression.

Obvious limitations of this study include lack of diversity in the test population. More than half of the participants were male (54%), 60% were 65 years old or older, 75% were married, 73% were Caucasian, and 79% were Protestant. Data indicated that 61% were not local, local being defined by zip codes in Durham, NC and surrounding counties (Pearce et al., 2012). No mileage range was given so locality is slightly vague. Furthermore, if location is a variable, it would be important to know if the participants were natives of the area or the length of their residence.

Another potential limitation of this study (Pearce et al., 2012) was the short form of the depressive survey was used. The shorter version was chosen because according to Pearce et al. (2012) previous studies with cancer patients have shown that brief assessments yield better results with cancer patients. The authors felt this might be a limitation because depression might be a confounding influence when trying to measure desired spiritual care compared to received spiritual care.

The 11-item spiritual needs survey Pearce et al. (2012) developed was not validated. After seven participants had joined the study, eight more questions were added. So for this part of the study $N = 143$ not 150. Out of the 19 total questions, 8 were taken from previously validated measures.

According Pearce et al. (2012) this is one of first studies to examine the connection between depression and spiritual care received. They believed that providing patients with desired spiritual care will reduce patient suffering. Creating interventions

that are appropriately matched with patients' needs is "an important next step in advanced cancer patient care" (Pearce et al., 2012, p. 2275).

Sirilla and Overcash (2013) designed a study to examine the quality of life (QOL), spiritual well-being, and supportive care resources for cancer patients who had undergone hematopoietic stem cell transplant (HSCT) and their caregivers. They followed the progress of 159 participants over 6 months, administering the survey at the 1-month, 3-month, and 6-month intervals post HSCT. The study was divided into three basic groups, those who received allogenic treatment (stem cells from a donor), those who received autologous treatment (their own stem cells), and the group overall.

The study utilized the Functional Assessment in Cancer Therapy—Bone Marrow Transplant (FACT-BMT; Version 4) to measure QOL, the Functional Assessment of Chronic Illness Therapy—Spiritual—12 scale (FACIT-SP-12; Version 4) to measure spiritual well-being, and a resource questionnaire (Sirilla & Overcash, 2013, p. 1139). The FACT-BMT version 4 and the FACIT-SP-12 Version 4 are both valid and reliable measures. The resource questionnaire Sirilla and Overcash (2013) developed to measure three specific areas of social support: Assistance/Support, Alternative or Spiritual Support, and Support Group. The resource questionnaire was designed using yes and no answers with a place to write in details if the participant selected 'Yes'.

Participants were selected from a "Bone Marrow Transplant Unit at a National Cancer Institute-designated hospital in the Midwestern aspect of the USA" (Sirilla & Overcash, 2013, p. 1139). Further hospital or location designation was not revealed. This

is a potential limitation of the study since attitudes and perceptions vary regionally and this was not factored into the study.

The participant pool was primarily made up of White (90%), married (69%), males (59%) over the age of 50 (36%). Only five Asians and 10 African Americans were included in this study. No socioeconomic data were collected (Sirilla & Overcash, 2013). Unfortunately, no religious demographics were recorded from this study. Neither was there any information regarding how or how well families utilized the resources they were given.

Sirilla and Overcash (2013) found that patients' primary source of spiritual resources was from their physician or nurse. Participants reported that faith, prayer, and spiritual healing were utilized by 63% of individuals in this study, followed by relaxation at 37%, and yoga and aromatherapy were reportedly least used by participants (Sirilla & Overcash, 2013). If there was a definition for spirituality, it was not disclosed in the article.

Sirilla and Overcash (2013) found a decrease in QOL in the 30 days following the HSTC for all participants. They found patients with low spirituality scores reported higher rates of depression. Most participants reported an increase in QOL that surpassed their baseline at the 6-month interview. However, allogenic patients showed the lowest QOL at the 1-month survey, showed the slowest improvement in QOL scores, and did not return to their baseline QOL by the 6-month interview (Sirilla & Overcash, 2013). The authors speculated that because allogenic HSTC patients were the most likely to experience complications such as graft versus host disease and other serious physical

impairments their scores remained consistently lower than autologous patients (Sirilla & Overcash, 2013).

There is a correlation between QOL and spiritual needs that has been observed in a number of studies (Abu-Raiya et al., 2015; Best et al., 2016; Sirilla & Overcash, 2013). Based on the results from this study, Sirilla and Overcash (2013) recommended future research that would include studying patient perception of possible support systems including spiritual interventions. Patients want more open communication regarding their spiritual needs and healthcare providers need to be more sensitive to these needs (Sirilla & Overcash, 2013).

This is important since 85% of their participants reported information regarding spiritual resources was obtained from their physician or their nurse (Sirilla & Overcash, 2013). Seventy-two percent of these participants reported that they made use of this information and 61% reported using brochures obtained from the physician's office (Sirilla & Overcash, 2013).

The importance of spirituality in healthcare has been established, however the role of the physician regarding spirituality is less clear. With the reintroduction of the BPS-S model into health care, the entire health care team has been asked to play a larger role in discussing spiritual needs with patients and providing for those needs (Best et al., 2015). In an extensive literature review, Best et al. (2015) reviewed 54 studies, which included 12,327 patients, to determine patient interest and satisfaction with religious or spiritual discussions with doctors.

Defining terms and concepts are a major problem, even in reviews, since not all authors define spirituality the same, not all participants understand it the same, and many use the terms spirituality and religion interchangeably. However, most researchers are now in agreement that religion is a subset of spirituality. Best et al. (2015) used the Puchalski et al. (2009, p. 887) consensus definition of spirituality in regard to healthcare as “the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (p. 1321).

Using this definition of spirituality as a base, three major themes were included in Best et al.’s (2015) literature search. They were: (a) patient-doctor communication, (b) patient preferences, and (c) spirituality and religion. Only English, academic publications of original research on adults regarding religion and or spirituality communication with doctors or patient preferences were included in the review. They did not include any date restrictions in their search criteria. Most of the studies reviewed (79.6%) were conducted in the United States, but all were from industrialized countries. Best et al. reported that demographic information on all participants was incomplete but the mean age of participants (when demographic information was collected) was 55.7 years old and the mean number of females was 54.3% (p. 1324). Religious affiliations, when collected, included: Christian, Jewish, Muslim, Buddhist, Agnostic, spiritual not religious, and indigenous Australian. Best et al. (2015) found an extensive assortment of measures were used from study to study to assess these themes.

Thirty-nine of the studies Best et al. (2015) reviewed were quantitative, but because of the diversity of the studies, meta-analysis was not conducted. From the 15 qualitative studies, they attempted to correlate key words and phrases into the quantitative data. Once the data extraction was completed from both qualitative and quantitative studies, Best et al. collated their findings.

Best et al. (2015) identified four major themes. The first was a “desire for a holistic approach” (Best et al., 2015, p. 1324). Patients reported the need to feel respected as a unique individual by their physician. They further reported wanting non-medical dialogue and discussions with their physician in which their physician would come to know them as a person, not just a patient. Physician initiated prayer was addressed in 15 studies and was met almost completely favorably. Researchers found an increase in interest in religious or spiritual communication and interaction the corresponded to the severity of the illness.

The second major theme identified was “disempowerment” (Best et al., 2015, p. 1324). Regardless of the perceived evolution in the physician-patient relationship models, many patients reported feeling inferior to their physicians especially in regard to knowledge of their condition and options. Patients reported feeling vulnerable and uncomfortable opening a more personal discussion (Best et al., 2015). The four models of physician-patient relationship identified by Emanuel and Emanuel (1992) seem to meld when patients are faced with a terminal illness. Many patients reported a desire for reciprocated respect from their physician that includes compassion and empathy (Best et al., 2015). Due to the complicated nature of the physician-patient relationship, many

patients looked to their physicians to initiate conversations of religious or spiritual nature (Best et al., 2015). Participants from one study revealed “feeling vulnerable” about having spiritual discussions with their physician while in the hospital because they were in a hospital gown (Best et al., 2015, p. 6). Other barriers patients reported were “not believing it was their job” and worrying their physicians were not interested (Best et al., 2015, p. 1326). Some patients reported the fear of death discouraged them from initiating a spiritual conversation with their physician.

The third major theme was “spiritual guidance” (Best et al., 2015, p. 1324). While patients may desire religious and spiritual dialogue from their physicians, these researchers found that many prefer the actual intervention to come from designated religious officials such as chaplains. Patients reported wanting honest communication, where they were considered equals to their physicians regarding spirituality, not feeling they are being proselytized. Their findings included that patients desire more voluntary collaboration with their physicians regarding spiritual issues.

In some cases, religious beliefs overlap practical care and treatment. Depending on religious restrictions and participation some populations would have benefited from these discussions from the practical perspective of being able to coordinate diet with care. Several studies focusing on Muslim patients highlighted patient dissatisfaction with a lack of spiritual communication and coordination of their customs and beliefs such as Ramadan fasting (Best et al., 2015).

The fourth major theme was “spirituality and healing” (Best et al., 2015, p. 1324). These researchers found that spirituality was central to patients coping and spiritual

communication with their physicians was viewed as an affirmation from their physicians. Many patients reported disappointment when physicians did not engage in this dialogue (Best et al., 2015, p. 1324). They did find a “significant minority, (greater than 50% in 6/38 papers [sic])” that were opposed to religious or spiritual conversations with their physicians (Best et al., 2015, p. 1324). These individuals reported (a) not being seriously ill or (b) have an established spiritual support system. From the qualitative literature they reviewed, Best et al. (2015) discovered a number of patients reported believing part of spirituality was the divine component of healing and that God would work through their physician.

Overall, the results of Best et al. (2015) study were mixed. One of their key findings was a lack of working definitions. They did report a significant discrepancy between the patient perception of spiritual needs and the physician perception. According to Best et al. (2015) patients reported a rise in spiritual needs that was consistent with the progression of the disease and the nearing of death. However, they also found that most patients preferred to have spiritual consultations with clergy. Spiritual discussions with physicians were desired to help personalize the patient.

Yoo et al. (2014) reviewed 120 studies on women coping with breast cancer, published between 1980 and 2012. Thirty-three articles met the inclusion criteria for further review. This included 15 quantitative studies, 17 qualitative studies, and one mixed methods study. Yoo et al. limited the scope of their review to examine these questions: “(1) What is known about coping with breast cancer among major racial/ethnic

groups? (2) What are the strengths and limitations in the research on this topic to date?” (p. 811).

Although Yoo et al. (2014) discovered ethnic differences in how women coped with cancer, they found spirituality as a coping mechanism to be a common theme in both the qualitative and quantitative studies they examined (p. 820). Yoo et al. concluded: “Many people with cancer suffer because health-care professionals lack understanding of the cultural and environmental contexts in which they live” (p. 821). Yoo et al. suggested further research is needed to help education those in the medical profession with regard to culturally specific coping mechanisms.

In an exploratory qualitative study, Lynn et al. (2014) conducted in-depth interviews with 47 African American women who had been diagnosed with breast cancer, stage O, I, or II, and completed primary treatment. This study was focused on three major themes: “(1) attendance at religious services, (2) comfort through the prayers of others, and (3) encouragement through reading Biblical scriptures” (Lynn, et al., 2014, p. 1713). Lynn et al. found 87% of these women used at least one religious or spiritual practice as a coping technique. Research questions were focused on positive aspects of religion and spirituality so study participants did not report any negative religious or spiritual impacts. Questions were also limited from diagnosis through survivorship, so Lynn et al. suggested future studies include end of life scenarios. Lynn et al. recommended the inclusion of health care professionals in assessing spiritual distress, emphasizing the importance of these health care professionals in their ability to link cancer patients with resources.

Patient Comfort in Communication With Physicians

Current studies indicate patients desire communication with their physicians about spirituality, but most are uncomfortable bringing the subject up and want their physicians to broach the subject first (Astrow et al., 2018). In previous studies, many patients felt inferior to their physicians and reported feeling “disempowerment” (Best et al., 2015, p. 1324). Patients also reported feelings of vulnerability and were uncomfortable starting more personal discussions but expressed a desire for these conversations to occur (Best et al., 2015).

Studies have shown the majority of patients felt it would be more comfortable if physicians initiated spiritual conversations (Pearce et al., 2012). Patients reported that even a polite inquiry as an opening for this communication regarding spiritual needs from their physician, such inquiries not only made the patient more comfortable but also lowered the incidence of depression (Pearce et al., 2012). Interestingly, another study found 85% of their participants received spiritual resources from their provider or provider’s office (Sirilla & Overcash, 2013). This area was explored in this study through several open-ended questions as to what participants’ experiences have been in discussing spirituality with their physician and what they feel would make the experience of discussing spirituality more comfortable with their physician.

Negative Impacts of Religion or Spirituality

Religion or spirituality can play a vital role in improved coping, increased healing, and overall well-being, but there can also be a negative impact or negative coping caused by religion or spirituality (King et al., 2013). Termed by some as

religious/spiritual struggle, some patients report increased depression, lower quality of life, and reduced physical functioning because of negative religious or spiritual coping. Patients who experience religious/spiritual struggle report “feeling abandoned by God, punished by God, and angry with God” (King et al., 2013, p. 994). Since many physicians are hesitant to discuss religion and spirituality with their patients, patients with negative religious or spiritual coping face a greater challenge accessing resources that could bring them relief.

King et al. (2013) designed a study to measure the religious/spiritual struggle in cancer patients about to undergo bone and marrow transplants using the Rush Religious Struggle Screening Protocol (Rush Protocol; Fitchett & Risk, 2009) and compared it with results from social workers personal interviews. During their first week after admittance in the bone and marrow transplant program, 178 participants from the Seattle Cancer Care Alliance were given the Electronic Self-Report Assessment-Cancer (ESRA-C; Berry, et al., 2014) and an in-depth psychosocial assessment from a social worker. Limited demographic information was also recorded. Most of the participants were White (83%), male (53%) with a mean age of 51.7 years old (King et al., 2013, p. 994). Marital status was not recorded.

King et al., (2013) found that a personal interview with a social worker produced nearly twice as many requests for a chaplain than the Rush Protocol (34 vs. 17 %, respectively). Conversely the Rush Protocol elicited an 18% positive response to religious or spiritual struggle, compared to 0% when interviewed by social workers. King et al. speculated that patients were more uncomfortable disclosing religious or spiritual

needs personally but had fewer inhibitions when using a computer survey. King et al. also noted that while social worker interviews had a general inquiry into religious or spiritual struggle, they were cursory and had very limited definitions and language to evaluate religious or spiritual struggle (King et al., 2013).

King et al. (2013) stated this study was not designed as “a definitive test of the Rush Protocol” but indications are clear that it could be a useful screening tool (p. 999). King et al. also stated that further research is needed to help determine if patients who identify themselves as spiritual but not religious are more likely to suffer from negative religious coping than those who define themselves as both. Spiritual and religious screening could be used to help physicians find an opening to discuss these issues with their patients.

Summary and Conclusions

While there is a substantial body of work that has been conducted on this topic, there are still major gaps that contribute to a limited understanding of how, when, and how much spiritual care patients are looking for from their medical team (Best et al., 2015). As King et al. (2013) found, the inclusion of screening tools could greatly benefit physician communication facilitating better patient care. But greater demographic breadth is required to gain a clearer understanding of what patients want. Many of the researchers have used limited populations that consist of elderly, married, Caucasian, Protestant patients (Pearce et al., 2012). Cancer is not limited to this demographic, so research must include all those impacted. Clearer definitions of religion and spirituality need to be

developed. In order to best serve their patients, physicians need to be able to communicate about these concepts.

The purpose of this study was to examine how cancer patients of different ages, gender, urban/ rural, and religious backgrounds view their ability to communicate with their physicians about spirituality. Not only does the incidence of cancer continue to increase, but with better treatment, patients are surviving longer. There is a known connection between spiritual wellbeing and physical wellbeing, but research indicates this connection is sometimes overlooked in certain populations. To address that gap the approach used a qualitative study to scrutinize in-depth how survivors perceived their spiritual needs and communication with physicians during their treatment.

The aim of this study was to better understand the lived experiences of cancer survivors and their perceived spiritual needs and communication with their physicians. Results of this study could increase cancer patients' quality of life, the quality of life of their families and support groups and improve provider care options.

In this chapter, I provided a review of the literature and described how the current study will help fill the gap(s) in the literature, as identified by previous researchers. In Chapter 3, the research method for the study, the rationale for this method, and how this method helped fill the gap(s) in the literature will be described. In Chapter 3, I will also discuss the setting, population, instruments, and the analysis process used.

Chapter 3: Research Method

According to the U.S. Cancer Statistics Working Group (2024), approximately 430 individuals out of every 100,000 will be diagnosed with cancer. Survival rate variables include the type of cancer; the stage at diagnosis; the treatment; and individual variables, such as age, overall health, and access to treatment (National Cancer Institute, 2020). In the United States alone, there were approximately 16.9 million cancer survivors in 2019, and the National Cancer Institute (2020) predicted that number will be close to 22.2 million by 2030. As more and more people survive cancer, it becomes more important to understand their experiences and how these experiences relate to survivors' well-being. The purpose of this study was to examine the lived experiences of cancer patients' communication with their physician about spirituality while battling cancer.

In this chapter, I describe the research design and rationale, role of the researcher, methodology, participant criteria and selection, instrumentation, recruitment, and ethical concerns addressed for this population. The data collection and analysis plans and limitations are also discussed in this chapter.

Research Design and Rationale

The research question that guided this study was: What are the lived experiences of patients communicating with the physician about spirituality while in treatment for cancer? The main concept I addressed in this phenomenological study was the participants' comfort level in communicating with their physicians about their spiritual needs while they were undergoing treatment for cancer.

Research has shown that while patients desire more spiritual communication with their physicians, they are unsure how to bring up the topic (Astrow et al., 2018). Increased spiritual care corresponds with shorter recovery and better overall physical and mental health (Hatala, 2013). Currently, there are a limited number of models to provide physicians with a theoretical framework to help include spirituality into the provision of a more holistic health care (Anandarajah, 2008).

There have been a number of studies conducted around this topic, but there are still notable gaps in the research (Best et al., 2015). One potential gap in research was that most previous studies have been conducted in limited geographic locations, meaning there was virtually no diversity in the populations studied (Pearce et al., 2012). I hoped the current study would address this gap by including a more diverse national sample recruited from social media. Another gap found by Ramondetta et al. (2013) was a lack of clear, working definitions regarding topics such as spirituality and religion. Rego and Nunes (2016) found that most research does not delineate between religion and spirituality but addresses them as one and the same. Another gap is there are few measures that are useful in examining this aspect of healing from cancer (Sirilla & Overcash, 2013).

Central Concepts

The central concepts of this qualitative study were the lived experiences of cancer survivors' communication experiences with their physicians, including how the participants define the concepts of spirituality and religion, how they live these concepts, what they expected from their physician, and what they experienced. Another concept of

focus was how these experiences impacted the participants' perceptions of overall health. I examined these concepts examined using the BPS-S model as a framework for holistic health (see Sulmasy, 2002).

Research Design

In this study, I employed a qualitative phenomenological design. This study was based on the assumption that there was an essential experience shared by participants that would help with an overall understanding of this lived experience (see Merriam & Tisdell, 2015). Using a phenomenological design for this study allowed for an in-depth exploration of the experiences shared by cancer survivors and facilitated a better understanding of their needs.

Rationale

The phenomenological design was the most appropriate for this study because the participants' shared experience was the topic I wanted to explore. The participants met the inclusion criteria (see Rudestam & Newton, 2006). Use of the narrative design would have limited the number of participants with no way to generalize about this population (see Rudestam & Newton, 2006). A grounded theory design would not have been appropriate for this study because of the time constraints that may be involved with data collection (see Rudestam & Newton, 2006).

Role of the Researcher

As the researcher, my role was to maintain a balance of impartiality, curiosity, and bias while observing and documenting the behavior and body language of the participants being interviewed. I was responsible for recruitment, data collection and

analysis, and dissemination of the findings. I ensured the participants were provided with resources in the case they became dysregulated. The collected data are securely stored and will continue to be until their destruction 5 years after the completion of this study.

While I might have had some preconceived suppositions, I remained as impartial as I could (see Stadtlander, 2018). I did not have personal experiences with cancer, which mitigated any potential for researcher contamination from sharing or the possibility of researcher dysregulation. As the researcher, it was my duty to approach this topic with an open mind and as few assumptions as possible (see Stadtlander, 2018).

Participant Selection

Participants had to be at least 18 years old and have been previously diagnosed with Stage 2 cancer or higher that is now in remission. Participants also had to be fluent in English. I recruited the participants from online social media sources as well as through printed flyers and word of mouth. The interviews were expected to last approximately 30 minutes to 1 hour.

Procedures

Prior to the interviews, I briefed the participants on the study's intent and specifics, including the informed consent form, my contact information, and their right to withdraw from the study at any time. The informed consent form contains researcher and university contact information to allow the participants the opportunity to ask questions and ensure their complete understanding of the purpose and design of the study as well as data handling. The participants were also provided with resources should they become dysregulated during or after the interview.

I collected demographic information regarding the participants' age, gender, urban/rural, and religion. Information regarding cancer type and remission were also be collected for screening purposes. The data were stored on my secured thumb drive. Participants were debriefed after their interview and provided with support resources.

Data Collection

Data were collected via in-person or email interviews. For the interviews that were conducted online, I used a health insurance portability and accountability act (HIPAA) compliant video conferencing software version of Zoom. Depending on the loquaciousness of the participant, the interviews lasted between 30 to 60 minutes. Each participant was interviewed one time, but all were agreeable to be recontacted if further questions had surfaced.

I conducted the interviews using a semistructured outline with a list of interview questions and additional prompts if needed. The interviews were voice recorded using the Zoom record feature to aid in the data analysis. As the researcher, I also took notes to ensure that the participants' body language and facial expressions were documented.

In qualitative phenomenological studies, the researcher assumes participants are experiential experts; therefore, the sample size is significantly lower than quantitative studies (Rudestam & Newton, 2006). For this study, I recruited 10 participants, but content saturation was met at nine participants (see Rudestam & Newton, 2006). Participants' identities were kept confidential, and their participation was voluntary, not paid.

Data Analysis

Merriam and Tisdell (2015) suggested that best practices include an ongoing evaluation of the data as they are being collected. I continued to gauge if the interview questions were providing the quality of information that was required, making sure that participants defined key topics in sync and that their stories stayed on track. The data from the interviews were a combination of digital voice recordings with researcher notes and journaling.

The data analysis began when reading the transcript of the first interview and category construction was started (see Merriam & Tisdell, 2015). As I coded the data, I looked for patterns that led to larger themes, which ultimately resulted in the findings (see Merriam & Tisdell, 2015).

Once the interviews were completed, the Zoom audio recordings were transcribed into a Microsoft Word file. From there, I entered the information into a Word table and scrubbed the data for grammatical errors, stuttering, and transcription inaccuracies. Word and Zoom were HIPAA-compliant tools that allowed for data analysis and coding. Zamawe (2015) stressed that any qualitative software program is a tool to help researchers understand and make sense of data, not a device that will analyze the data for the researcher.

Trustworthiness

Credibility, transferability, dependability, and confirmability are all considerations qualitative researchers need to take into account to ensure that data are accurate, can be transferred to a more generalized population, are reproducible, and

objective (Stadtlander, 2018). One possible threat to credibility in this study was volunteer bias. Even within the population of cancer patients, those who volunteer may not be representative of the general population. Asking participants about their motivation for participation is one way to reduce this threat. Prolonged contact is another way to reduce the impact of selection or volunteer bias. Triangulation, the use of multiple data sources, is another consideration that can be reduced by a thorough literature review of the measures to be used. Researcher bias is a potential threat to credibility as well. This threat was reduced by using an interview script that will limit the potential for experimenter behavior or cues to unintentionally contaminate participant responses.

Verification of Findings

Regardless of the research approach, quantitative, qualitative, or mixed methods, the study should be investigating what it claims to be (i.e., validity) and have the capacity to be reproduced with nearly the same results (i.e., reliability; Merriam & Tisdell, 2015). There is a frequent debate about socioeconomic influences that may influence what is valid and reliable. According to Merriam and Tisdell (2015), much of this debate can be reduced to the concept that valid and reliable research seeks to understand. By using transparent and ethical methods, open-mindedness, incorporating other research and reviewing relevant literature, and current findings, I ensured that the findings of this study are valid and reliable.

Ethical Considerations

To prevent the possibility of including a vulnerable population, cancer survivors in remission were recruited. I did not make any contact with prospective participants until

this study had been approved by the Walden University Institutional Review Board (IRB). Participants were given full disclosure prior to participating. They were advised of their right to withdraw from the study at any point without penalty as well as to the type of data that would be collected and how they would be stored. They were also given resources should they feel the need for greater services or counseling after taking part in the study.

The participants will remain anonymous. Data will be stored in a secure, password-protected thumb drive in a locked office for 5 years and then destroyed. I did not identify any conflicts of interest in this study. No incentives were given to participants.

Summary

Spirituality is becoming a greater consideration within the medical community; however, spiritual communication between cancer patients and their physicians is frequently lacking to the satisfaction of the patient (Ramondetta et al., 2013). The following research question guided this study: What are the lived experiences of patients communicating with the physician about spirituality while battling cancer? Participants were invited to take part in this voluntary study if they met the inclusion criteria. Once data were collected from participant interviews, the data were coded, sorted, and processed through Word software. Results from this study could provide a greater understanding of the lived experiences of this population and shed light on improvements that could be made to help increase their life satisfaction and expectancy.

In Chapter 3, I described the research design, methodology, and measures taken in this study. Participant requirements and sampling procedures were outlined. The results of the study and analysis of the data will be discussed in Chapter 4. In Chapter 5, I will provide an interpretation of the findings, the limitations of the study, my recommendations, and implications.

Chapter 4: Results

As cancer survival rates continue to rise (National Cancer Institute, 2020), understanding peoples' expectations from their health care providers becomes increasingly important. According to Astrow et al. (2018), more cancer patients feel the need for spiritual support but are unsure of what is available or how to attain it. There is a growing body of research that indicates there is a connection between spiritual, emotional, and physical health (King et al., 2013).

In this qualitative phenomenological study, the research question was What are the lived experiences of patients communicating with the physician about spirituality while battling cancer? Before interviews began, participants answered 11 demographic and screening questions. Once participants met the screening criteria, they were interviewed with a series of either 15 or 13 questions depending on if they had spiritual communication with their physician or not. I developed these questions to prompt participants to share their experiences, definitions, and satisfaction or lack thereof during the process of cancer treatment.

Data were collected through a combination of in-person and email interviews. I conducted the interviews using semistructured interview questions with variable follow-up questions and prompts. All participants agreed to later interviews for clarification, if necessary.

The results of this study could help positively impact cancer treatment outcomes and patient well-being. Physicians, hospitals, and all other medical care providers could use the results of this study to better understand their patients' needs and be proactive in

helping patients access resources that can lead to higher QOL outcomes. This study increases the body of knowledge regarding spiritual communication between patients and physicians and could ultimately lead to better communication and life satisfaction for patients.

In Chapter 4, I describe the pilot study, setting, participant demographics, data collection and analysis processes, and the evidence of trustworthiness. I also provide detailed information regarding the results of this study, including the research design and procedures. Chapter 4 ends with a summary.

Pilot Study

Two pilot study subjects agreed to be interviewed to help determine if my interview questions were appropriate and thorough enough. This pilot study allowed me to assess the length of the interviews more accurately and highlighted a potential problem with my original line of interview questions. After the pilot interviews, I determined that a separate interview track needed to be constructed for individuals who did not have any spiritual communication with their physicians. I devised the following conditional branching question to help increase the information I could gather: Did you get any spiritual support from your physician? (If yes, answer the following questions. If no, skip to next section.). The Walden University IRB, my committee chair, and my committee member were consulted after the pilot study to ensure the additional questions were ethical, transferable, and replicable.

I conducted the pilot study interviews in person and audio recorded them using the HIPAA-compliant Zoom platform, and the recordings were then downloaded into

Word for transcription. After being downloaded, the Zoom recording was deleted. Once the interviews were transcribed, I cleaned the transcripts for grammar and coded them for analysis.

Setting

I conducted this study using in-person and email interviews. Participants were recruited using a combination of flyers, social media posts, and word of mouth. Although a number of recruitment methods were used, most of the participants came from the snowballing effect where one participant shared the study and my contact information with someone they knew. I contacted potential participants via the phone to confirm their interest and ensure that they met the inclusion criteria. Once this was established, we scheduled an interview time and location. I traveled to the location and used my laptop to record the interview and paper to take notes. Before the interview began, the participants were given the informed consent form and an introduction to the study. Once the informed consent form was signed and completed, the actual interviews were conducted. The in-person interviews were recorded using a HIPAA-compliant Zoom platform, then downloaded and transcribed by Word. I took notes during the interviews to ensure I had a clear understanding of the participants' answers. The transcribed interviews were cleaned for grammar errors and downloaded to a thumb drive. The Zoom recordings were then deleted.

One participant was adamant about using email to ensure she had enough time to reflect on the questions and be as thorough as possible. Email participants were sent an email with the informed consent form and asked to respond with an email that stated, "I

consent.” These participants were then emailed the interview questions with instructions. Once their responses were returned, I transferred them into Word and deleted the original emails.

The in-person interviews lasted an average of 45 minutes. I recontacted three of the in-person participants for follow-up interviews, which only lasted a few minutes to clarify a particular question or point. None of the email interviews were recontacted.

Demographics

I had participants answer 11 demographic/screening questions. Participants in this study ranged in age at the time of diagnosis from 34 to 88. Of the nine participants, there were eight women and one man. Five were married, one was single, and three were widowed at the time of their treatments. One was a high school graduate, three had some college, one had an associate’s degree, two had bachelor’s degrees, and two had master’s degrees. All nine participants were White. Five had breast cancer, one had renal and rectal cancer, one had thyroid cancer, one had soft tissue sarcoma, and one multiple myeloma. One woman was diagnosed twice, 34 years apart, with different cancers, breast and then colon. Six participants were not given a stage of their cancer during the diagnosis. Four were treated in Florida, two in Tennessee, one in South Carolina, one in Maryland, and one in Colorado.

To maintain confidentiality, I randomly numbered the participants. Table 1 shows the participant number, age, gender, ethnicity, education, marital status, location of treatment, and if they were interviewed in-person or via email.

Table 1

Demographics

Subject #	Age	Age at diagnosis	M/F	Education	Marital status at the time	Location when treated
1	63	61	F	Bachelors	Single	Tampa, FL
2	86	62	F	High school	Married	Baltimore, MD
3	88	88	F	Some college	Widowed	Jacksonville, FL
4	74	34 and 68	F	Some college	Widowed	Jacksonville, FL
5	89	57	M	Bachelors	Married	Jacksonville, FL
6	80	62	F	Associate degree	Married	Germantown, TN
7	86	74	F	Some college	Widowed	Knoxville, TN
8	62	61	F	Masters	Married	Littleton, CO
9	78	55	F	Masters	Married	Manning, SC

Data Collection

Prior to data collection, I obtained Walden University's IRB approval; the approval number is # 03-20-24-0189576 and it expires on March 19, 2024. My objective was to better understand the lived experiences of cancer patients' communication with their physicians regarding spirituality. Using social media, flyers, and word of mouth, I had 12 people volunteer to participate; however, data saturation was met after interviewing nine participants.

To participate, volunteers had to be at least 18 years old, fluent in English, previously been diagnosed with Stage 2 cancer or higher, and currently in remission and not being treated. The rationale being I wanted to use adult subjects, I only speak English, patients currently being treated are considered a vulnerable population, and Stage 2 cancer or higher could cause spiritual/religious distress and include the fear of dying. Six of the nine participants were not given a "stage" at diagnosis. Participant 2 stated "I was told, 'It's bad, but we caught it early.' And it was a double mastectomy.." Participant 5

reported, “They told me it was a large malignant mass that had to come out immediately. It scared me.” Since the rationale behind Stage 2 cancer or higher was that diagnosis might increase spiritual/religious distress, I made the decision to include these participants.

I contacted the participants by phone to confirm their interest, verify they met the inclusion criteria, and set up an appointment time and place. Interviews were conducted from October 4, 2023 to December 2, 2023. Six interviews were conducted in-person and three interviews were conducted via email.

In-person interviews began with a review of the informed consent form and an introduction to the study. Participants agreed to approximately 90-minute interviews, but most averaged between 30 and 45 minutes. Once the informed consent forms were signed, I advised the participants that the interview would be recorded and offered them the opportunity to remove themselves from the study. All agreed to complete the study. Participants were then asked a series of in-depth interview questions that had been developed to better understand their lived experience (see Appendix B). The interviews were audio recorded using a HIPAA-compliant Zoom platform. I downloaded these audio recordings into Word and transcribed them. The transcribed interviews were then transferred to a thumb drive, and the original recordings were deleted.

Four participants stated they preferred email interviews. Participants 8 and 9 stated they wanted to use email due to physical limitations, while Participant 3 stated she wanted to have several days “to mull this over” so she could be as thorough as possible.

One potential email participant did not respond after I sent them the informed consent form, and I could only assume they chose not to continue in the study.

I emailed the email interview participants the informed consent form and an introduction to the study, and they provided their consent by replying with a response of “I consent.” They were then emailed the interview questions and instructions, and I encouraged them to contact me if there were any questions. They were also agreeable to having me follow up with them if I had any questions regarding their responses. They returned their interview responses and did not contact me with any questions nor did I have to reach out to any of them. Their email responses were downloaded to a Word file and a thumb drive, and the original emails were deleted.

During the in-person interviews, all the questions were answered, and none of the participants became emotionally dysregulated. I provided all participants with contact information for National Alliance for Mental Illness and encouraged them to reach out if they felt any discomfort or distress after the interview. All the email interviewees answered all of the interview questions.

To begin with, participants answered 11 demographic/screening questions. The next part of the interview addressed the research question with a series of either 15 or 13 questions. I used conditional question branching depending on if they had spiritual communication with their physician or not (see Appendix C).

Data Analysis

I began my data analysis by organizing the interview transcripts. I started by constructing a table where I randomly assigned participants a number, assigned each

participant a row, and constructed a column for each of the demographic questions. The next step was to construct a second table where each participant was again assigned a row and each interview question was assigned a column under which the participants' transcribed answers were entered in their entirety. I had a final column for coding from the participants' answers. Using that information, I made another table with yes/no answers regarding if the participants were spiritual, if they had any spiritual conversations with their physicians, if they wanted any, and if they used any community resources.

I transcribed the interviews in Word and needed to clean them for grammar errors and double check them against my notes for accuracy. Once the tables were completed, I read and re-read the interviews a number of times to look for patterns, discrepancies, and similarities, paying attention to what the participants may *not* be saying (see Stadtlander, 2018). I started the coding process by highlighting information that was similar in nature in one color and discrepancies in another color. From the precise codes, I then developed categories and themes.

Evidence of Trustworthiness

Qualitative research is considered trustworthy if it establishes a clear trail of credibility, transferability, dependability, and confirmability (Stadtlander, 2018). In a qualitative study, credibility confirms that data collected are as accurate as possible, while transferability indicates data collected can be generalized to other populations (Stadtlander, 2018). Dependability and confirmability are comparable to the quantitative research concepts of reliability and objectivity, meaning that the study could be

reproduced and researcher bias did not interfere with the study construction or data collection (Stadtlander, 2018).

Tracy (2010) established eight criteria for conducting qualitative research that would satisfy the four standards that establish trustworthiness. To increase the current study's trustworthiness, I kept these eight criteria in mind while developing the study: (a) I believe I picked a worthy topic, (b) I conducted it with rigor, (c) I approached it with sincerity and (d) credibility, (e) I believe this information will resonate with several audiences, (f) I believe it can make a significant contribution, (g) I followed all ethical guidelines, and (h) I believe that the literature review has meaningful coherence (see Tracy, 2010).

Results

The purpose of this study was to examine the lived experiences of patients communicating with the physician about spirituality while in treatment for cancer. I collected demographic information from the participants information and screening purposes. There were two different interview question tracks depending on whether the participants had communicated with their physicians or not.

Table 2 shows the type of cancer, stage if it was given, if the participant considered themselves spiritual or religious, if the participant worried about death when they were diagnosed, if the participant had any spiritual communication with their physician, if they wanted that communication, and if they were aware of or used any community resources. The participants' complete interview answers were much more in-depth and detailed, and those will be examined further.

Table 2*Cancer/Spiritual Information*

Subject number	Cancer type	Stage	Are you spiritual/religious	Did you worry about death	Did you have spiritual conversation w/Dr	Did you want spiritual conversation w/Dr	Were you aware of or use community resources
1	Breast	??	Yes	No	No	Yes	None
2	Renal rectal	??	Yes	No	No	Maybe	None
3	Thyroid	??	Yes	No	No	UKN	None
4	Breast	??	Yes	Some	No	Maybe	None
5	Colon	??			Yes	Yes	
5	Soft tissue sarcoma	??	Yes	No	No	Maybe	None
6	Breast	??	Yes	Yes	Yes	Maybe	None
7	Breast	3	Yes	No	Yes	No	None
8	Breast	2	Yes	Yes	No	No	None
9	Multiple myeloma	3	No	Yes	No	No	None

Note. ?? = the subject was not informed of the stage of cancer at the time of diagnosis.

There were a number of themes that became evident as these interviews were examined with several subthemes. The first theme that was identified was the lack of cohesive definition or understanding of spirituality. The second theme was the participants' expression of their spirituality. The third theme was their consideration of death when diagnosed. The fourth theme was who they relied on for their primary spiritual support and if they felt these needs were met. The fifth theme was the desire to have their physicians initiate spiritual conversations. Three subthemes were identified: (a) they did not have any spiritual conversations with their physicians; (b) participants were not uncomfortable talking to their physicians; and (c) they were not aware of additional community resources. The sixth theme identified was participants believed that having a spiritual conversation with their physician would have benefited them.

Theme 1

The first theme that became apparent was the lack of concrete definition of spirituality or even religion. In some instances, the same participant used the terms interchangeably. Other participants did not differentiate between the two. The first interview question was: How do you define spirituality? Five of the participants included God or a Higher Power in their definition; three included actions for others; and two included searching for meaning in life.

Subject 1 reported “Spirituality is a feeling, it's an emotion. It's that you believe in something that will help you and provide you guidance and love and stability in life.”

Subject 3 said:

The definition of spirituality is a vague concept at most. Does going to a place of worship weekly make one spiritual? I feel a person can have a spiritual side but not attend a place of worship weekly. One's early upbringing and environment can nurture a spiritual side.

Theme 2

The second theme that emerged was how the participants expressed their spirituality. The interview questions were: Do you consider yourself spiritual (or religious)? If so, how do you express your spirituality? Do you belong to any spiritual or religious groups (church)? These questions added greater depth to the subjects' definitions of spirituality and religion.

Eight of the nine participants defined themselves as spiritual and use Christianity as their base. Seven of the nine attend church services and report either daily prayer or

scripture reading or both as a way to express their spirituality. Eight of the nine had attended church regularly either currently or at some point in their life. Subject 1 said,

I believe in God and so I pray a lot, multiple times a day for different times and different events that happen. Whether it's asking for help or to be thankful for guidance and things that have been given to me that I believe came through God.

Subject #8 stated,

I have always been spiritual and have explored several religions to fulfill that. I currently don't belong to any church but consider myself Christian in that I believe in Jesus Christ and specifically only what he communicated, not anyone else, including any of the apostles, and I somewhat question validity of scriptures.

Theme 3

The third theme was their consideration of death when diagnosed. The interview questions were: When you were diagnosed, did you worry about dying? If so, how did it impact you? How did it affect you spiritually?

Five of the nine subjects reported not having a fear of dying. Two participants reported some fear of dying due to younger children in their homes. The subjects used similar phrases such as “putting it in God’s hands,” “asked for God’s help,” “my faith was always strong,” and “turned to God.” Subject 1 said, “Actually, when I was diagnosed, I did not worry about dying. I was more shocked.” Subject 3 reported, “I would like to think that (with) my diagnosis I did not think about death. Quality of life became a serious consideration, but death no longer upsets me.” Subject 6 stated:

Yeah, I think I did because my husband had died. And I didn't want to leave my children because they still were all at home. I would say yes, that I became closer to God and I asked for his help and all.

Subject 8 said,

I was more concerned about leaving people behind, like surviving family members and friends. Spiritually, I would say, it brought a little closer to my mortality. But since I know we all will die someday, of something, I did not have fear and still don't.

Theme 4

The fourth theme was who they relied on for their primary spiritual support. The interview question was: Who did you rely on for your primary spiritual support?

Five of the nine participants reported they relied on immediate family members who were identified as partner, husband, daughter, son, parents, and family. Three reported they relied on their church community, church friends, or pastor. In addition, eight of the nine participants specifically discussed prayer, church, or both in how their primary support helped them during this time. Subject 1 said,

You know, you begin, you know, praying, asking for guidance, asking for support through prayer. I didn't seek, you know, if I spoke to a couple of close family members. You know that they all said, you know, we'll pray for you. I don't think that I wasn't as vocal about what was happening to me as maybe some other people that have cancer. You see people rattling around them and prayer groups. I didn't have that piece. I kind of had my own. And then I had close friends that

knew what was going through this. And, you know, we'll say prayers for you or something's coming on, you know, we'll do prayers. But I didn't have a large group.

Subject 8 said, "Prayer from family and friends was a great comfort and source of support, so I asked for that and did receive it."

Theme 5

The fifth theme was the desire to have spiritual conversations with their physicians. Three subthemes were identified: (a) they did not have any spiritual conversations with their physicians, (b) participants were not uncomfortable talking to their physicians, and (c) they were not aware of additional community resources.

Theme 5 was identified using the fork question: Did you get any spiritual support from your physician? The subthemes were identified using the following interview questions: Did you feel uncomfortable discussing spirituality with your physician, if so, why? Would you have liked to have been able to have spiritual conversations with your physician? What kind of community resources were available to you? How frequently did you use these resources?

Subtheme 1

Using the interview fork question: Did you get any spiritual support from your physician? Seven of the nine participants reported not having any spiritual discussions with their physician. Subject 1 stated,

No, because there were so many different physicians. There was no longevity time that I felt that there was time to talk about the spiritual part. Only when you

went into surgery, if something happened, they asked, you know, what is your religion? There was no face to sit down and have a conversation with. The guy who performed the surgery, there was none, and then the doctors that you're referred to, it was more of what the process was going to be. There was not the communication of anything else.

Participant 3 said,

Thinking back on my introduction to the many doctors I visited at Mayo not one has mentioned spirituality. Interesting to consider why this is, because they did not want to get too close to their patients? Not get too involved, just treat them for a specific field they excelled in, be socially correct? Remember, don't discuss religion or politics. Perhaps with a variety of opinions about religion and diverse religions that cover the globe it is a difficult subject to approach. Not wanting to offend anyone or get their blood pressures up, it's considered best to avoid the subject of religion and death?

Subtheme 2

The second subtheme identified was participants were not uncomfortable discussing spirituality with their physicians. The interview question was: Did you feel uncomfortable discussing spirituality with your physician and if so, why? Seven of the nine reported they were not uncomfortable having spiritual discussions, but Subject 4 reported, "The doctor has to be the one to initiate. The fact that he knows what you're going through, he knows the better person that would help you..."

Subtheme 3

Using the following interview questions the third subtheme was identified: What kind of community resources were available to you? How frequently did you use these resources? Eight out of nine participants were not aware of additional community resources. Subject 8 said, “My health care offered support groups, but I didn't feel like I needed that. The oncology unit offered soft, knitted hats for free, so I did take and use those a lot.” Subject 9 said, “There were no community resources that I knew of - I had tremendous support from my family and my friends.”

Theme 6

The sixth theme was determined using the interview question: How would discussing spiritual concerns with your physician changed your experience? The sixth theme identified was participants believed that having a spiritual conversation with their physician would have benefited them. Seven of the nine participants reported they would have benefited from spiritual conversations with their physician. One reported she did not mind the separation of physical and spiritual because she wanted her physician focusing on her physical health because that was his specialty. The only subject who was not spiritual reported no desire to speak with her physician about it. Subject 1 said,

I would have liked the encouragement, or some direction, or even a pamphlet that had options of, you know, to see things out. I did join a cancer group that they had, that you could ask questions about, and they had some guidance and connection of people, but my physician did not provide any.

Subject 4 said, “It would have been nice to know they were in my corner. And knowing that they were in the same realm as I am. That there would be something else there behind them besides their skill.”

Subject 4 had cancer twice, 30 years apart. She reported during her second cancer that she knew her physician personally. Subjects 6 and 7 also knew their physicians personally. Subject 4 reported her second physician was a deacon at her church. Subject 4 reported she and her physician did not have any conversations but said:

You kind of knew that he had you in his corner. Maybe a little expert extra.

Anyone knows that he might, you know, possibly be one of these that prays for his patients, you know, that maybe not with you, but maybe.

Subject 6 reported she and her physician did not have any conversations but said, “Well, I actually knew him as a friend, and I knew he was Christian. I was glad he was the one that was going to be operating on me.”

Subject 7 said:

The only thing that I remember is that before the surgery he had a prayer with me. Before surgery and all he would pray with me. It was emotional, you know. I was glad that he was a Christian and he was because I felt like he might intend to God and that would help.

Discrepant Cases

Subjects 4 and 9 are discrepant cases. Subject 4 was diagnosed with breast cancer at age 34 and colon cancer at age 68 and reported different experiences in each instance.

Subject 4 said:

My first cancer, they (my doctor) don't want to be with you. They don't. They don't want to. They don't want to be by your side. But professionally, he was excellent. But he could have been a little bit more compassionate. Now my colon cancer was different. My colon was after the breast. Because my surgeon was Christian. And that he was more spiritual minded and attainable, he didn't mind. Of course, he wouldn't go into religion as such, but he would always wish you well and say "God be with you" or you know, whatever he thought my ease my mind as to what was going to happen next.

Subject 9 was the only participant who was not spiritual or religious. Subject 9 reported she was not uncomfortable communicating about spirituality with her physician, she just had not desire to discuss the subject. Subject 9 reported, "I am not particularly spiritual or religious - I do not attend church." Subject 9 said, "If I had spiritual discussions with my physician, I doubt it would have changed my attitude and/or approach to my cancer."

Summary

In Chapter 4, I defined the purpose of the study and the research questions. I reported on the pilot study. I described the study setting and the participant demographics. I reported on the data collection and analysis. I reviewed my strategies for maintaining credibility, transferability, dependability, and confirmability. I identified the major themes and presented supporting data. Demographic tables were included in Chapter 4.

Chapter 5 includes the significance of the study and the key findings. The data will be examined and interpreted in the context of the theoretical framework and applied to the existing body of knowledge. Limitations of the study are reviewed. Recommendations for future research and positive social implications are provided.

Chapter 5: Discussion, Conclusions, and Recommendations

According to the ACS (2024), nearly 2 million new cases of cancer will be diagnosed in 2024. Fortunately, with improved detection and treatment methods, more patients are surviving cancer than ever before (Miller, 2019). There is a direct correlation between decreased rates of depression and anxiety and increased QOL in cancer patients (King et al., 2013). The traditional separation between spirituality and physical health may increase cancer patient anxiety and depression (Dein et al., 2010). Understanding the needs of cancer patients will improve their overall outcome and the quality of life of their support systems (Krug et al., 2016).

In this qualitative phenomenological study, I interviewed nine cancer survivors who were no longer in treatment about their lived experiences in communication with their physicians regarding spirituality, their comfort in communication, and their needs. This study was conducted to help understand cancer patients' needs, help improve the QOL for future cancer patients and their support systems, and help physicians better understand patient expectations.

Interpretation of the Findings

The BPS-S model was the theoretical lens for this study. Sulmasy (2002), Anandarajah (2008), and Hatala (2013) agreed that the BPS-S could be a useful framework to help physicians include spirituality in a more holistic approach. The largest problem of the BPS-S identified in the literature review in Chapter 2 was the lack of clear definition for the concept of spirituality. From Speed's (2013) definition that includes social justice to Kaur's (2013) transpersonal reality, the current study's participants

reported an equally broad spectrum of definitions. Subject 1 said, “Spirituality is a feeling, it’s an emotion.” Subject 2 said, “I was always brought up in the Church.” Subject 4 stated, “The definition of spirituality is a vague concept at most.” A lack of concrete definition of spirituality has been linked to the problem of how to address spiritual or religious concerns for patients as part of the reason that many physicians neglect this realm of their patients’ lives. However, it is possible that the definition is not as relevant as previously thought. There is a growing body of research that supports the idea that patients want to be treated holistically. However, the results in the current study do not suggest that patients expect their physician to treat their spirit as well as their body but perhaps to act as the gatekeeper for resources. Subject 1 said,

I think it would have benefited, because I think that there are so many questions going through your head, even if it was a guidance in the fact of you know you might want to contact. You know, a priest or somebody, you know that you feel comfortable talking with and I didn’t have my own church and I didn’t have my own pastor, even though I went to church, mine was more one-on-one conversation, you know, with my God and me. So, I would have liked the encouragement, or some direction, or even a pamphlet that had options of, you know, to see things out.

This study also confirmed the problem that much of the existing research addresses religion and spirituality as one concept (see Rego & Nunes, 2016). Subjects 2, 3, 4, 5, and 6 used the terms interchangeably and used religion to define their spirituality.

When asked to define spirituality, Subject 4 replied, “I’m a Christian. I believe in God, and I believe he is Almighty and he can do miracles and he has.”

Rosequist et al. (2012) found that spiritual cancer patients reported an increase in the concept of spiritual surrender that increased their positive outcomes. In the present study, the findings confirmed that spiritual cancer patients reported they did not fear death, either at all, or in the same way the nonspiritual participant reported. Subjects 6 and 8 reported fear of leaving small children behind, while Subjects 1, 2, 3, 4, 5, and 7 stated they did not have a fear of death. Subject 7 said:

No, I guess I just felt whatever this is, is what I live with, OK. I just felt all along if I was meant to have it then I would be taken care of. It would either be or not. I would live or I wouldn’t.

Subject 9 reported she was not spiritual or religious and said, “I did worry about dying for a few days, but I have always been a person who faces my problems and works to find ways to solve them.” Subject 9 was singular in that she reported she solved her own problems when all other participants described turning to their faith or a belief system that included other people for support. According to Hatala (2013), individuals with higher levels of spirituality are likely to have better overall health, recover faster, and have fewer mental health problems.

The current study also confirmed the perceived separation between medicine and spirituality (see Best et al., 2016). Subjects 1, 2, 3, 4 (first cancer), 5, 8, and 9 reported never having any spiritual conversations with their providers. Subject 4 with her second cancer and Subject 6 had some spiritual communication with their physicians only

because the physicians were known to the participants from their churches. Subject 7 said,

The only thing that I remember is that before the surgery he had a prayer with me. Before surgery and all, he would pray with me. It was emotional, you know. I was glad that he was a Christian and he was because I felt like he might intend to God and that would help.

The present study also confirmed the findings of Pearce et al. (2012), Best et al. (2015), and Astrow et al. (2018) in that most patients felt they would have benefited from some spiritual conversation *initiated* by the physician. Subject 4 reported of her first cancer 34 years ago:

Back then, doctors did not speak of spirituality. Mine did not. He was very straightforward. Very professional. Very one of these types that did not want to get involved but wanted to do his work. So therefore, he did not really explain a whole lot other than what the principle was and what was going to need to be done and how it was going to be done.

Subject 4 went on to say:

It would have been nice to know they were in my corner. And knowing that they were in the same realm as I am. That there would be something else there behind them besides their skill. The doctor has to be the one to initiate. The fact that he knows what you're going through, he knows the better persons that would help you as far as maybe referring you back to pastor or whomever.

The findings of the current study supported the themes identified by Best et

al. (2015) regarding patients' desire for a more holistic approach, feelings of disempowerment, spiritual guidance, and spirituality and healing. Subject 1 said,

They do it so often, that they talk to patients, that they still just need to understand that it's the first time, you know, for many people and then, you know, maybe ask the question is, you know, spiritually, do you need, you know, us to give you contact information and I don't know that he would have been the best person to talk to me spiritually about it but I think he could have given me guidance on the appropriate people to do that though.

Limitations of the Study

For this qualitative phenomenological study, I wanted to examine the lived experience of cancer patients and their comfort in communicating with their physicians about spirituality. Originally, I planned on conducting a quantitative study using 159 participants who would answer an online survey anonymously. After 3 months of advertising on different social media and reaching out to different cancer and religious organizations with no response, I decided that the study would need to be altered to a qualitative phenomenological study. One of the biggest limitations of this study, inherent in a qualitative phenomenological approach, was that there was very little variance in demographics. It would be interesting to see how different age, gender, and socioeconomic groups respond to the questions asked in this study. Although I used social media, including cancer survivor groups, to solicit for participants, most of the subjects came from the snowball recruitment technique.

Another major limitation of this study was that several of the participants were advancing in years, and in some cases, more than 30 years had passed since their cancer treatment experience. It is possible many of these memories have faded or mellowed with time, making them less important or less accurate.

Another limitation is possible self-censoring. Because there have been social and cultural changes during this time, it is possible participants fearing the current cancel culture sought to report their experiences in line with current ideologies rather than accurately depicting their actual experiences (Hu & Barradas, 2023). Several of the subjects were reluctant to discuss some of the interview questions in-depth possibly due to those woke factors. Subject 3 said, “Remember, don’t discuss religion or politics.”

Recommendations

Based on the results of this study, I recommend that more research be conducted regarding the public perception of spirituality. Older generations admit to limitations discussing topics such as religion and politics. Subject 2 said, “We were just raised that way; you didn’t talk about it.” It is questionable whether the current cancel-culture and woke culture is likewise limiting personal opinions for fear of social judgement from younger people or from physicians. Rego and Nunes (2016) found an increasing number of people who consider religion to be a cultural or social identity, and spirituality as an inner self-journey. How people define these terms is one indication of how they experience the phenomenon. A wider range of demographics would increase the knowledge base regarding spiritual needs across socio-economic, age-related lines.

Another recommendation would be to include the at-risk population of patients currently in treatment. Subjects in this study may not have been able to accurately remember the intensity of their needs and emotions with time and distance between them and their treatment. Subject 1 reported, “I think they increased a lot. I don’t think I was very vocal about what I needed at the time.” A longitudinal study of patients and their spiritual needs, from diagnosis through survivorship, could provide more information that could result in a much larger positive social change.

I also recommend that more research be dedicated to the personal support systems of cancer patients as well their perceived needs for themselves and cancer patient family members. Krug et al. (2016) found that the better the QOL experienced by the cancer patients, the better the quality of life of their families and friends. All nine subjects in this study reported that their family and friends were their main source of emotional and spiritual support.

Implications

This study highlighted the potential impact for positive social change on several levels. One area of possible positive change could be in the coordination of care. Subject 1 said, “You have to fill out ‘Religion’ on the intake form and then nobody ever asks you about it again.” Perhaps physicians’ offices could follow that up with a few more questions and a few more resources, which could improve the QOL for the patient and their family/support system. This would also alleviate some of the awkwardness surrounding the topic of communicating about spirituality for the physician (Best et al., 2016, Ramondetta et al., 2013).

Another level of social positive change would be for the cancer patient. When asked what kind of community resources were available to them and how frequently they used them, Subject 5 said, "I didn't know of any, but I probably would have used some." According to Meluch (2018), a patient's perception of their health and ability to communicate with their physician is filtered through their spiritual philosophy. Patients have indicated they want their physician to acknowledge spirituality is an aspect of their patients' lives and be capable of providing necessary resources (Best et al., 2016).

Finally, this study could create a positive social change by increasing awareness of support groups, community resources, and support for support groups for the family and friends who form the backbone of the support for cancer patients. According to King et al. (2013), increasing spiritual health directly corresponds to improved emotional and physical health. Krug et al. (2016) found a correlation between improved QOL of patients and improved QOL of their families.

Conclusion

The purpose of this study was to understand how cancer impacted individuals from a spiritual perspective and if their medical team was aware of any spiritual needs they had and incorporated those needs into treatment options. This qualitative phenomenological study comprised a combination of in-person and email interviews with nine individuals who survived cancer. The results of this study confirmed a number of findings from previous studies.

Possibly one of the most important takeaways from this study was that while there is not a conclusive definition of spirituality, for the purposes of improving patient quality

of life, there may not need to be one. Rather than feeling the responsibility of spiritual counseling or conversation, it is more important for the physician to merely identify there is a spiritual need and help their patient coordinate with spiritual support care. Subject 4 said,

The doctors sometimes don't realize how much that one-on-one time means, other than just numbers. They don't want to take you into account as a person, or what you might need. I mean, they don't always express that to you. I feel like people that are going through something of a life-death situation need to be dealt with kid gloves, that they do need more compassion. They need to know that you're there. They need to know that you can give them the right resources should they need to find something they're looking for. He may not be able to give it to you, but they may be able to refer you to someone.

More research needs to be done on this topic. In the meantime, the results of this study show that none of the participants, including the nonspiritual subject, would have been opposed to their physician asking them if they had any spiritual needs and providing the subjects with something as simple as an informational brochure about local resources.

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Appendix A: Demographics

1. How old are you today?
2. Have you been diagnosed with cancer:
3. How long ago were you diagnosed?
4. Are you currently receiving chemotherapy or radiation?
5. Where were you living when you were diagnosed?
6. What is your gender?
7. What is your race/ethnicity?
8. What is your highest degree?
9. Marital Status?
10. What type of cancer were you diagnosed with?
11. What stage were you diagnosed at? What stage are you at currently?

Appendix B: Interview Questions

1. How do you define spirituality?
2. Do you consider yourself spiritual (or religious)? If so, how do you express your spirituality? Do you belong to any spiritual or religious groups (church)?
3. When you were diagnosed, did you worry about dying? If so, how did it impact you? How did it affect you spiritually?
4. Who did you rely on for your primary spiritual support?
5. How did your spiritual needs change as you went through treatment?
6. Did you get any spiritual support from your physician? (if yes, following questions. If no, skip to next section.)
7. What kind of spiritual support did you get from your physician? How was the support you had from your physician?
8. What kind of spiritual discussions did you have with your physician?
9. How frequently did you discuss spirituality and your needs with your physician? Was it enough?
10. How comfortable were you discussing spirituality with your physician? How would you rate your satisfaction in discussing spirituality with your physician?
11. How important was it for you to have your physician involved in the spiritual aspect of your treatment?

12. How did your communication with your physician about spirituality impact your overall treatment?
13. What would you have changed in regard to communicating with your physician about spirituality?

Did you get any spiritual support from your physician? (if no, answer these questions):

7. Did you feel uncomfortable discussing spirituality with your physician, if so, why?
8. Would you have liked to have been able to have spiritual conversations with your physician?
9. Were your spiritual needs met, and if so, who helped you?
10. What kind of community resources were available to you? How frequently did you use these resources?
11. How would discussing spiritual concerns with your physician changed your experience?