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Spiritual Care in Cancer Genetic Counseling: Patient Perceptions of Methods

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Spiritual Care in Cancer Genetic Counseling: Patient Perceptions of Methods

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Abstract

The integration of spirituality into medical care is a growing area of debate among professionals, involving a delicate balance between serving patients who may benefit from this without alienating those who would not. To date, little research has targeted spirituality in cancer genetic counseling, particularly concerning the various methods a genetic counselor can use to address spirituality with their patients. A paper questionnaire was created and distributed to patients following their cancer genetic counseling appointments to gain insight on their perception of these methods. Fifty-two participants completed this questionnaire. The eight different spiritual integration methods presented each showed positive responses by the participant group on average, though opinions varied between participants. The method with the highest approval involved a genetic counselor informing patients that spirituality was a welcome topic of discussion during their appointment. Overall, 78.9% viewed this as a positive action by the counselor, while 11.5% viewed this negatively. Higher participant approval was typically seen for more indirect methods of addressing spirituality, and some methods were more beneficial for Christians compared to Non-Christians. Interestingly, 48.1% of patients indicated that they did not desire the genetic counselor to address their spiritual needs, with only 23% responding that they did. The fact that this item was presented before the potential methods may indicate a misconception that spirituality and genetics are incompatible. This study highlights the many opportunities for further research into this topic.

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Chapter 1

Review of Literature

[1]Spencer, C. M., Edwards, J., DeGregory, C., Brooks, K. (2018). Spiritual assessment in genetic counseling: Patient perception of methods. *Journal of Genetic Counseling*. To be submitted.

1.1 Concepts and Techniques of Spiritual Care

1.1.1 Overview

Spirituality is a broad concept for which there are many different interpretations. Some equate spirituality with religion specifically, while others include nonreligious belief systems, life meaning, and/or metaphysical phenomena under the definition (Hughes et al., 2017). In 2013, a panel of experts provided a unified definition of spirituality as "a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices (Puchalski et al., 2014, pg. 644)." This definition differentiates spirituality from religiosity. Although religious beliefs and traditions can be an important component of spirituality, many other types of personal and existential beliefs are also considered to be spiritual.

1.1.2 Rationale for spiritual care

The idea that there is a connection between health and spirituality is not new, with some studies dating back to the 1800s. Studies vary in design and explanatory mechanisms, but overall show a trend between religious involvement and positive health outcomes (Ellison & Levin, 1998). Even studies designed to display skepticism towards this trend acknowledge that there is a relationship between religious/spiritual factors and overall health, although they indicate that more specificity is required when studying this relationship (Thoresen & Harris, 2002). Among the medical community, there are mixed perceptions of the influence of spirituality. One study found that slightly over half of

physicians believed that religion and spirituality had positive effects on patient outcomes, and these effects were mainly emotional rather than physical (Curlin, Sellergren, Lantos, & Chin, 2007). Some argue that spirituality is such a broad subject that implementing it into clinical care at all is unreliable (Bash, 2004). Nonetheless, study of spirituality and medicine has expanded rapidly since the 1990s. This has caused a much wider acceptance of spiritual care as a necessary part of health care, especially in palliative care, due to the potential to provide comfort to dying patients (Puchalski et al., 2014).

One of the primary motivators for the practice of spiritual healthcare is patient desire. Ehman, Ott, Short, Ciampa, & Hansen-Flaschen (1999) concluded that roughly two-thirds of patients agreed that physicians should ask about spiritual beliefs if the patient should become gravely ill, while only 16% disagreed. Furthermore, nearly half of the patients that did not have strong spirituality welcomed the question (Ehman et al., 1999). Another study examined the spiritual needs of hospitalized patients, finding that 64% agreed that doctors should address spiritual needs with their patients. In addition, the authors noted that 83% of patients utilized religious coping, and 30% reported that they experienced religious/spiritual struggles in relation to their hospitalization (Ellis, Thomlinson, Gemmill, & Harris, 2013). MacLean et al. (2003) observed that among their participants, one-third desired integration of spirituality into routine office visits, increasing with worsening severity of their disease. The literature on spirituality has identified that a large group of patients want medical professionals to talk about spirituality when medical crises occur.

Another major benefit of spiritual care is the management of spiritual interpretations that may be harmful to patients. Research indicates that spirituality can

have negative consequences in patients who interpret their situation in a maladaptive way. Bjorck & Thurman (2007) studied religious coping in patients, or the use of religious beliefs as a source of relief in times of crisis. They showed that although positive religious coping is more common than negative religious coping, the latter can cause decreased psychological functioning and increased depression. Furthermore, positive and negative religious coping can occur simultaneously with complex, erratic consequences (Bjorck & Thurman, 2007). When crises occur, patients can manifest negative religious coping in multiple ways, including religious apathy, assuming they are being punished, anger towards a supernatural being, religious doubts, interpersonal religious conflict, and conflict with their chosen dogma. These reactions can inhibit their ability to cope with their disease (Pargament et al., 1998). For some patients, it may be helpful for clinicians to recognize these "red flags" for spiritual distress and refer the patient to chaplains or other appropriate resources (Pargament et al., 1998). Both the positive and negative impacts of spirituality in patients have prompted professionals to study ways to standardize delivery spiritual care.

Several other justifications for spiritual care have also been identified by researchers, such as increased patient satisfaction and openness to treatment. Some researchers have identified religious barriers to holistic medical care that may influence patients' medical decisions, and these barriers may be mitigated by appropriate spiritual care. Different religious groups have dissimilar views on the cause and meaning of illness, with many interpreting these events as acts of God. People with these beliefs may be less inclined to seek treatment outside of the spiritual realm. Addressing medical issues within the context of a patient's worldview may cause them to be more open to

treatment (Cornetta & Brown, 2013). Another benefit of spiritual care is increased patient satisfaction. Hodge, Salas-Wright, and Wolosin (2016) conducted a large-scale study regarding the relationship between spiritual care and overall satisfaction with medical care in older patients. Their cohort of 4112 adults age 65 and older significantly perceived their medical care as more satisfactory if their spiritual needs were addressed (Hodge, Salas-Wright, & Wolosin, 2016). However, achieving the positive effects of spiritual care involves significant challenges.

1.1.3 Barriers to spiritual care

Despite these perceived benefits, many physicians do not perform spiritual care; many reasons are given for this. One of the most prominent explanations for the lack of spiritual care by medical professionals is a lack of training in the subject (Balboni et. al., 2013). Measures have been taken to address this concern and increase the frequency of spiritual care. The Clinical Pastoral Education for Healthcare Providers (CPE-HP) is an example as a training program designed to increase healthcare providers' skills with spiritual care. Although it has not reached widespread implementation, initial results have been promising. A study of this program's efficacy showed a marked increase in ability, frequency, comfort, and confidence in providing spiritual care after completion of the program. Confidence in providing spiritual care to those with different beliefs increased more than confidence in providing it to those with similar beliefs. This is important to note, since differing spiritual beliefs can also be a barrier to spiritual care (Zollifrank et. al., 2015). Utilizing training such as this on a wider scale could potentially increase the use of spiritual care in the medical community.

Another notable barrier to spiritual care is the paucity of literature regarding aspects of spirituality other than religiosity. The currently accepted definition of spirituality was only agreed upon in 2013, and previous research on spirituality in medicine overwhelmingly focused on issues of religion and faith rather than other personal and existential beliefs (Puchalski et al., 2014). In addition, many healthcare providers still conflate spirituality and religion, much like the general population. More research and education on comprehensive spirituality would undoubtedly improve the prospect of providing spiritual care. Using the tools created by spiritual care specialists may guide spiritual integration in more general fields.

1.1.4 Assessments/interventions

The techniques of implementing spirituality in a clinical setting vary greatly. Physicians should be prepared to offer spiritual care or other spirituality-related referrals if the patient requests them. They should also convey respect and sensitivity towards patient beliefs (Post, Puchalski, & Larson, 2000). Tanyi, McKenzie, and Chapek (2009) interviewed 10 medical professionals to identify themes in the delivery of spiritual care. These professionals included family practice physicians, nurse practitioners, and physician assistants. Four common themes emerged in their cohort: displaying a genuine and caring attitude, encouraging the use of existing practices and spiritual beliefs, discerning instances for spiritual overt assessment, and managing perceived barriers to spiritual care. Some of these individuals also documented spiritual care as continuity of care (Tanyi, McKenzie, & Chapek, 2009). Researchers have discovered several reasons that medical professionals should be prepared to provide more active spiritual care,

involving the use of specific techniques to identify a patient's spiritual concerns and/or provide appropriate interventions.

The active integration of spirituality into the medical domain by the professional is most commonly done through spiritual assessment. Spiritual assessment is defined as "eliciting a client's spiritual and religious history" (Sperry, 2001). Potential benefits of performing a spiritual assessment include enhanced understanding of the patient's worldview, increased ability to convey empathy, discovery of healthy or unhealthy spiritual views, identification of spiritual resources, and planning of appropriate interventions to benefit the patient (Richards & Bergin, 1997). Many different spiritual assessment tools have been developed to guide professionals in this process. The simplest of these is FICA (Post et al., 2000), which is displayed in Table 1.1. Another spiritual assessment tool is the HOPE tool (Saguil and Phelps, 2012), seen in Table 1.2.

These are only two of the many spiritual assessment tools that exist. Other tools of this sort tend to be longer and more targeted to specific settings or situations. A simpler method to bringing spirituality into the medical realm is the Open Invite Mnemonic, which provides several approaches to two main goals. This tool is summarized in Table 1.3 (Saguil & Phelps, 2012).

Once the topic of spirituality has been opened, healthcare providers have a range of options in terms of direct intervention. However, they must carefully consider the appropriateness of each intervention and tailor their approaches to the patient's comfort level. Some clinicians are comfortable having a discussion with a patient about any spiritual issues they may have, using active listening to help them process their feelings.

Referral to resources is another common intervention strategy. Chaplains are specifically trained in the provision of spiritual care that is inclusive of all beliefs, so clinicians often refer patients to them when a spiritual crisis is identified. Spiritual support groups may also be helpful to patients when they are available. Some professionals are even comfortable praying with patients or taking part in spiritual activities, and this is greatly appreciated by certain patients. However, clinicians should use significant caution and tact when suggesting and engaging in such an overt spiritual activity, if they choose to do so. Poorly executed attempts may potentially offend patients (Hughes et al., 2017).

1.2 Spiritual Healthcare in Oncology

1.2.1 Rationale for spirituality as part of cancer care

Late stage cancer patients have been a population of interest in the study of spirituality. One study indicated that most cancer patients receiving palliative care relied on their religious/spiritual beliefs, and doing so increased their quality of life significantly. Palliative care is focused on providing comfort and relief to patients with a terminal illness (Vallurupalli, 2012). These patients indicated that attention to their spiritual concerns was an important part of their cancer care. Balboni et al. (2013) found similar results for late stage cancer patients, and also indicated that most nurses and physicians thought spiritual care should be provided at least occasionally. However, greater than 85% of these patients had never received spiritual care. Nurses and physicians indicated that a lack of training was the main reason that they did not provide this type of care.

Although much of the research focuses on patients with terminal cancer, some studies have shown that spiritual care can be beneficial in all stages of cancer care. A

large meta-analysis showed significant correlation between religious/spiritual factors and increased physical health, with no statistically significant differences in the relationship due to type, phase, or stage of cancer (Jim et al., 2015). Other studies have shown positive psychological effects along with physical ones. Aukst-Margetic, Jakovlievic, Margetic, Biscan, & Samija (2005) surveyed 115 breast cancer patients to investigate a potential relationship between religious faith, depression, and pain level in this population. Although religiosity was not associated with a decrease in pain perception, highly religious patients were found to have a lower level of depression. A large review of research on spiritual well-being and overall quality of life in adults with cancer found a significant association between these two factors (Bai & Lazenby, 2015). The 36 studies included showed an overall positive correlation between a high level of meaning/peace and mental/physical health. Religious belief alone was not consistently related to increased quality of life, and some reported negative associations. It is important to recognize that spirituality is more than just religiosity, and that being religious does not necessarily lead to better outcomes if the individual does not feel at peace.

Research has shown that spirituality may be particularly relevant in adjusting to cancer shortly after a new diagnosis. A large meta-analysis of 18 studies over 25 years showed a relationship between spirituality and maintaining or increasing well-being after a breast cancer diagnosis (Schreiber & Brockopp, 2012). However, specific conclusions about that relationship were difficult to make due to methodological differences in its constituent studies. Another study examined the possibility that perceived life threat may be a mediating factor in the relationship between spirituality and emotional well-being in newly diagnosed patients. They found that spirituality was associated with less distress

and better quality of life, regardless of how patients perceived their life threat (Laubmeier, Zakowski, & Bair, 2004).

Spirituality can have negative effects on adjustment to a cancer diagnosis if a person's spiritual needs are not addressed. One study examined this relationship with specific focus on identifying individuals who utilized negative religious coping. Of the 114 non-terminal cancer patients they surveyed, negative religious copers were found to have the highest depression. In contrast, those who were highly spiritual/religious showed the lowest depression. Although those with low spirituality had less depression than negative religious copers, they had the overall poorest adjustment to their cancer (Kristeller, Sheets, Johnson, & Frank, 2011). Thuné-Boyle, Stygall, Keshtgar, Davidson, & Newman (2012) demonstrated that religious/spiritual struggle can be a barrier to illness-adjustment in newly diagnosed breast cancer patients, indicating that related resources could be helpful in the coping process. These studies illustrate the potential benefit of identifying spiritual struggles soon after a cancer diagnosis, to help patients cope.

Overall, patients seem to find spirituality to be an appropriate and potentially beneficial part of their treatment, but the majority have not had it addressed. In addition, a sizeable minority feel that their care is inadequate without attention to spirituality. Astrow, Wexler, Texeira, He, and Sulmasy (2007) surveyed 369 outpatients at Saint Vincent's Comprehensive Cancer Center, and found that 73% thought it was appropriate for physicians to ask about spiritual needs. Despite this, only 6% of patients reported being asked about spirituality, and 18% claimed their spiritual needs were not being met. Patients with unmet spiritual needs reported lower satisfaction with their medical care.

Another study examined the frequency and consequences of unmet spiritual needs in patients with advanced cancer, and found that 91% of their cohort indicated they had spiritual needs. Seventeen percent of these patients claimed that they received less spiritual care than they desired from their healthcare providers, and these patients reported more depressive symptoms and less meaning/peace. The authors also found that 35% of patients would be more satisfied with their care if spiritual care was addressed (Pearce, Coan, Herndon, Koenig, & Abernathy, 2012).

1.2.2 Barriers to spiritual care in oncology

Medical professionals working with cancer patients recognize the potential benefits of spiritual care for these patients, but there are barriers that prevent this care from being consistently provided. A survey of the Multinational Association of Supportive Care in Cancer (MASCC) members regarding spiritual care showed that the majority of respondents thought that spiritual care was important in cancer care, mediated by the respondents' own spirituality. Forty percent of these respondents thought spiritual care was one of their roles as healthcare providers, while only 12% thought that it was not. However, 33% indicated that this did not provide adequate spiritual care, and 25% indicated they were not capable of doing so. As with other medical realms, a major barrier in cancer care is a lack of training (Ramondetta et al., 2013).

Another issue that has limited spiritual care in oncology is the focus on terminal cancer patients in the literature. The focus on spirituality in serious illness has caused a false perception that spirituality in healthcare is only applicable as a palliative measure for terminally ill patients. Some oncology researchers have been fighting this

misconception, insisting that spirituality is relevant in all stages of cancer care, although not all agree on the methods (Surbone & Balder, 2010).

1.2.3 Demographic considerations

Certain demographic variables may cause differences in spiritual needs that have important implications for medical and spiritual care. Moadel et. al. (1999) examined spiritual and existential needs in an ethnically-diverse cancer patient population to discover demographic trends. They found that Hispanic and African-American patients were more likely to have more than one spiritual need. Unmarried patients and recently diagnosed patients also showed this trend. Identified needs included overcoming fears, finding hope, finding meaning in life, finding spiritual resources, finding peace of mind, the meaning of life, and dying and death (Moadel et al., 1999). Another study looked at religious behaviors in colorectal and lung cancer patients, with particular attention to differences between African American and Caucasian patients in this population. Religious behaviors were associated with increased mental health and decreased depression in both groups, especially in women. However, the role of religion in these two groups varied somewhat. Religious behaviors were associated with more increased mental health and vitality in African Americans, while Caucasians showed more decreased depression. While the role of religious behaviors differs between individuals, it is important to recognize trends in different populations (Holt, Oster, Clay, Urmie, & Fouad, 2011).

In certain populations trends in spiritual behaviors can be associated with negative consequences that can impact medical care. One example of this is the prevalence of delayed diagnosis in highly spiritual African American patients. One study evaluated 129

African American breast cancer patients about their spirituality, breast cancer stage, and the time between their symptoms and diagnosis. They found that individuals who spoke to God only about their symptoms were less likely to seek medical care quickly, and had higher cancer stages. However, these individuals did not necessarily delay treatment after their diagnosis (Gullatte, Brawley, Kinney, Powe, & Mooney, 2010). This represents one of many populations with unique religious practices and beliefs, which medical professionals should be prepared to address in a culturally sensitive way.

1.3 Religion and Spirituality in Genetics

1.3.1 Overview

The interplay between spirituality and genetics is a complicated relationship that is not easily defined, particularly regarding religion. Despite the important implications both can have for an individual's life, there is little consensus among genetic professionals about religious issues, nor among religious leaders about genetics. Many on both sides tend to be unsure how to view the opposite field, and others see them as being in direct conflict. Bartlett & Johnson (2009) explored clinician and clergy perceptions of religion and genetics by conducting multiple focus groups with members of both professions. They found that in both groups, those that saw science and religion as complementary viewed fewer conflicts and more easily identified resources to deal with issues of faith and genetics. However, many participants could not identify these resources, and felt unprepared to deal with these issues as a result (Bartlett & Johnson, 2009). Despite the uncertain relationship between professionals in the two fields, genetics and spirituality do interact in a way that deeply impacts the lives and decisions of patients. Bridging this gap is vital for comprehensive personal care.

1.3.2 Research on spirituality in cancer genetics

The patient population for cancer genetics is unique in that some patients do not have a cancer diagnosis themselves, but may be at an increased risk to be diagnosed in the future. Referrals to cancer genetics are often made on the basis of an individual's family history of cancer. In addition to helping post-diagnostic patients adjust to their illness, research has indicated that spirituality may act as a heuristic in how patients cope with and interpret uncertainty regarding genetic cancer risk (White, 2009). Some evidence suggests that patients may be influenced by their spiritual beliefs when making decisions about genetic testing. One study looked at 290 women who had received genetic counseling for familial breast cancer, and assessed both their perception of risk and their level of spirituality. Patients who perceived their risk to be low, and those with high spirituality were less likely to undergo genetic testing. However, those with perceived high risk for cancer showed no significant difference based on spirituality (Schwartz et al., 2000). Similarly, Botoseneanu, Alexander & Banaszak-Holl (2011) concluded that among the general population, people with higher religious involvement had more negative views of genetic testing for disease. They indicated that tailoring messages about genetics to a person's spiritual worldview could potentially help overcome attitudinal barriers to genetic testing. Research has also shown that patients with higher moral-religious focus in their family environment show less psychological distress when undergoing BRCA1/2 testing (Keenan et al., 2004).

Spirituality affects patients outside of the realm of testing as well. Patients without a breast cancer diagnosis have been shown to have a lower perception of risk to get cancer when they have higher levels of spiritual coping. This can be defined as

reliance on spiritual beliefs or practices as a source of comfort in times of stress. The observed relationship was modified by family history (Quillin, McClish, Jones, Burruss, & Bodurtha, 2006). Another study showed that African American women with high risk for breast cancer may be less inclined to follow screening protocol if they consider themselves to be more religious (Kinney, Emery, Dudley, & Croyle, 2002). Those who are diagnosed with a genetic cancer predisposition syndrome seem to benefit from their spiritual beliefs. One study found that many Li Fraumeni Syndrome patients relied on their religious beliefs and community significantly to ease the emotional burden of the disease (Peters et al., 2016). Morris, Hadley, and Koehly (2013) showed that familial religious and existential well-being are tied to risk interpretation, communication about health concerns, and screening practices in families with Lynch Syndrome. These findings suggest that a spiritual assessment of some sort may be indicated for cancer genetic counseling.

1.3.3 Research on spirituality in prenatal genetics

Research in the prenatal setting has also indicated the relevance of spirituality to genetic counseling. Prenatal patients have been shown to have better long-term adjustment to a diagnosis with an increased ability to reconcile their spiritual beliefs and their actions in response to the diagnosis. Despite the importance of these issues to patients, they often will not bring them up independently, due to a misconception that these beliefs are not welcome in a genetic counseling appointment. For this reason, the authors suggested that genetic counselors invite patients to have a discussion about their faith (Anderson, 2009). The use of religious/spiritual language by the patient appears to be important to whether genetic counselors perceive a discussion of spiritual issues to be

warranted. Sagaser et al. (2016) found that 67% of patients in the prenatal setting were comfortable sharing their faith as it related to the appointment, and 93% indicated that they used positive religious coping. However, this study also described some limits to religious exploration in this setting, showing that less than 25% of the patients desired direct religious actions such as prayer or scripture exploration (Sagaser et al., 2016).

1.3.4 Demographic considerations

Similar to the relationship seen in cancer patients, spirituality and genetics can have unique implications for particular demographic groups that should be considered. These groups may benefit from culturally targeted counseling methods and discussion of particular spiritual issues. For example, African American women have been found to be more likely to use religious coping in response to an inherited risk for breast and ovarian cancer. Interestingly, those with fewer affected relatives tended to be more likely to use religious coping (Weathers et al., 2009). One study examined differences in perception of genetics from religious frameworks in African American and European American populations. Over half of the participants in this study indicated that God created genes, with more African Americans attesting to this. Among the people claiming this belief, only European Americans believed that God could not change genes after birth. Some participants in both groups indicated fear that geneticists were interfering in the realm of God. These results highlight a need to address religious concerns and misconceptions in genetic counseling, especially in groups that are more likely to be fearful of genetics (Harris, Parrott, & Dorgan, 2004).

Latin Americans and Arab Americans are two more demographic groups that are more likely to view genetics through the lens of their spiritual views, and this has

implications for genetic counseling. A study of Latina women at risk for mutations in BRCA1 and BRCA2 indicated that religious and cultural beliefs are a barrier to genetic counseling and testing. It was found that a strong belief in God's will may alter patient perceptions of genetic counseling (Sussner, Jandort, Thompson, & Valdimarsdottir, 2010). Another study within the Latin American community also found this association in people who were at risk for hereditary breast and ovarian cancer. The authors indicated that integrating religious leaders in the community into informing this population of genetic issues may help ease any perceived conflicts, as well as considering religious beliefs in counseling (Kinney, Gammon, Coxworth, Simonsen, & Arce-Laretta, 2010). Arab-Americans have been found to have a low rate of genetic testing for hereditary cancer overall. A study of Arab-American women regarding hereditary cancer risk found that a belief in "God's will" strongly influenced their perception of genetic counseling and testing. Prevalent cultural myths, such as a belief that cancer is contagious, also contributed to a lack of understanding in this group of participants. The authors advocate for culturally-targeted presentation of risks in genetic counseling in light of these results (Mellon, Gauthier, Cichon, Hammad, & Simon, 2013).

1.3.5 Rationale for study

The research on spirituality and health care describes a complex relationship between spirituality, medical decisions and outcomes. Recognition of this relationship in the genetic counseling community has caused some to recommend the integration of a spiritual assessment into the genetic counseling appointment (White, 2007). Over half of genetic counselors in one study reported that they had performed a spiritual assessment in the last year, but only 8.7% of them did so regularly (Reis et al., 2007). This study also

identified major barriers to regular implementation, including uncertainty about the role of spiritual assessment in genetic counseling, insufficient time, and a lack of skills. Two-thirds of these counselors reported that a targeted spiritual assessment tool would aid them in implementing this dimension into their appointments more frequently. It is important to note that genetic counselors are, on average, less likely to be religious than the general population (Cragun, Woltanski, Myers, & Cragun, 2009). This could potentially contribute to the lack of spiritual care in the field. However, a majority of genetic counselors still indicate that they are moderately to highly spiritual (Cragun et al., 2009). Even studies that convey skepticism towards regular integration of spirituality into the genetic counseling appointment acknowledge that there is a sizeable subset of the patient population that wishes to discuss their beliefs (Thompson et al., 2016).

The relevant literature has clearly demonstrated that spiritual assessment may be beneficial to both patients and counselors in cancer genetic counseling. However, few studies have targeted cancer genetic counseling patients specifically, and even fewer focus on the methods of integrating spirituality. This study aims to learn more about the specific needs and perceptions of patients in this setting, to clarify what methods of spiritual assessment and intervention they would find to be helpful and appropriate.

Table 1.1 FICA spiritual assessment tool

F: faith and belief	Do you consider yourself spiritual or religious?
I: importance	How important are these beliefs to you, and do they influence how you care for yourself?
C: community	Do you belong to a spiritual community?
A: address in care	How might health care providers best address any needs in this area?

Table 1.2 Hope spiritual assessment tool

H: sources of hope	-What are your sources of hope, strength, comfort, and peace? -What do you hold on to during difficult times?
O: organized religion	-Are you part of a religious or spiritual community? -Does it help you? How?
P: personal spirituality and practices	-Do you have personal spiritual beliefs? -What aspects of your spirituality or spiritual practices do you find most helpful?
E: effects on medical care and end-of-life issues	-Does your current situation affect your ability to do the things that usually help you spiritually? -As a doctor, is there anything that I can do to help you access the resources that usually help you? -Are there any specific practices or restrictions I should know about in providing your medical care? -If the patient is dying: How do your beliefs affect the kind of medical care you would like me to provide over the next few days/weeks/months?

Table 1.3 Open invite mnemonic

Open (i.e., open the door to conversation)	-May I ask your faith background? -Do you have a spiritual or faith preference? -What helps you through hard times?
Invite (i.e., invite the patient to discuss spiritual needs)	-Do you feel that your spiritual health is affecting your physical health? -Does your spirituality impact the health decisions you make? -Is there a way in which you would like for me to account for your spirituality in your health care? -Is there a way in which I or another member of the medical team can provide you with support? -Are there resources in your faith community that you would like for me to help mobilize on your behalf?

Chapter 2

Spiritual Care in Cancer Genetic Counseling: Patient Perceptions of Methods

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2.1 Abstract

The integration of spirituality into medical care is a growing area of debate among professionals, involving a delicate balance between serving patients who may benefit from this without alienating those who would not. To date, little research has targeted spirituality in cancer genetic counseling, particularly concerning the various methods a genetic counselor can use to address spirituality with their patients. A paper questionnaire was created and distributed to patients following their cancer genetic counseling appointments to gain insight on their perception of these methods. Fifty-two participants completed this questionnaire. The eight different spiritual integration methods presented each showed positive responses by the participant group on average, though opinions varied between participants. The method with the highest approval involved a genetic counselor informing patients that spirituality was a welcome topic of discussion during their appointment. Overall, 78.9% viewed this as a positive action by the counselor, while 11.5% viewed this negatively. Higher participant approval was typically seen for more indirect methods of addressing spirituality, and some methods were more beneficial for Christians compared to Non-Christians. Interestingly, 48.1% of patients indicated that they did not desire the genetic counselor to address their spiritual needs, with only 23% responding that they did. The fact that this item was presented before the potential methods may indicate a misconception that spirituality and genetics are incompatible. This study highlights the many opportunities for further research into this topic.

2.2 Introduction

Experts define spirituality as “a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience

relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices (Puchalski et al., 2014, pg. 644)." The connection between health and spirituality has been studied since the 1800s, showing a general trend that spiritual well-being is related to positive health outcomes (Ellison & Levin, 1998). There has been a rapid expansion of study in this area since the 1990s, which has caused a wider acceptance of spiritual care as a necessary part of healthcare (Puchalski et al., 2014; Curlin, Sellergren, Lantos, & Chin, 2007).

The integration of spirituality into the medical domain by professionals is generally done through spiritual assessment. Spiritual assessment is defined as "eliciting a client's spiritual and religious history" (Sperry, 2001). Potential benefits of performing a spiritual assessment include enhanced understanding of the patient's worldview, increased ability to convey empathy, discovery of healthy or unhealthy spiritual views, identification of spiritual resources, and planning of appropriate interventions to benefit the patient (Richards & Bergin, 1997). Many different spiritual assessment tools have been developed to guide professionals in this process. The FICA and HOPE tools are some of the more commonly used spiritual assessment tools, and both are acronyms representing stepwise templates for discussing spirituality with patients (Saguil and Phelps, 2012; Post et al., 2000). FICA stands for Faith, Importance, Community, and Address in care. HOPE represents Hope, Organized religion, Personal spirituality and practices, and Effects on medical care. Both provide the basic structure for a conversation about a patient's spiritual needs, though they take somewhat different approaches. For example, the FICA tool opens the conversation by asking directly if a patient considers

themselves to be spiritual or religious, while the HOPE tool asks about sources of hope and peace (Saguil and Phelps, 2012; Post et al., 2000). A simpler tool to address spirituality is the Open Invite Mnemonic, which guides professionals to convey openness to spiritual conversations and invite the patient to speak about their spirituality if they wish. This tool offers several opening options, such as asking an individual's faith background or what helps them through hard times (Saguil and Phelps, 2012).

Much of the research regarding healthcare and spirituality has been directed at cancer patients and spiritual care may be particularly relevant in patients with a recent diagnosis. Patients with high spiritual well-being following a cancer diagnosis tend to adjust better to their diagnosis, while those who experience spiritual struggles tend to have higher depression and poorer adjustment (Schreiber & Brockopp, 2012; Laubmeier, Zakowski, & Bair, 2004; Kristeller, Sheets, Johnson, & Frank, 2011; Thuné-Boyle, Stygall, Keshtgar, Davidson, & Newman 2012).

Patients have been shown to be influenced by spirituality when facing a genetic risk for cancer as well. Research has shown that patients with strong spiritual beliefs often have a more negative view of genetic testing, and therefore are less inclined to undergo testing themselves (Schwartz et al., 2000; Botoseneanu, Alexander & Banaszak-Holl, 2011). Conveying genetic information in a way that acknowledges their personal beliefs may help patients see its potential value (Botoseneanu, Alexander & Banaszak-Holl, 2011). Spiritual coping may be important to ease the emotional burden of a genetic predisposition for cancer (Peters et al., 2016). Conversely, patients who have strong spirituality and a predisposition for cancer may have a lower perception of their risk to develop cancer (Quillin, McClish, Jones, Burruss, & Bodurtha, 2006). This could

potentially lead to less consistent screening in these patients (Kinney, Emery, Dudley, & Croyle, 2002; Morris, Hadley, and Koehly, 2013). For these reasons, it may be beneficial to incorporate a limited spiritual assessment into cancer genetic counseling.

Despite the potential relevance to cancer genetic counseling, little research has focused on spirituality in this setting specifically, as research on spirituality in genetic counseling thus far has targeted the prenatal setting. Many prenatal patients have better long-term adjustment when they are able to reconcile a diagnosis with their spiritual beliefs. However, they may also feel that discussing their spiritual beliefs in a genetic counseling session is unwelcome without being invited to do so (Anderson, 2009). Positive religious coping is extremely common among patients in this setting, but it is important to note that only a small minority desires overt religious actions such as prayer (Sagaser et al., 2016).

In light of current research, some members of the genetic counseling community recommend the integration of spiritual assessment into genetic counseling (White, 2007). However, less than 10% of genetic counselors included in this study regularly acknowledged spirituality in their sessions. Identified barriers include insufficient training, inadequate time during appointments, and uncertainty about the role of spirituality in genetic counseling (Reis et al., 2007). However, research has indicated that genetic counselors are interested in a targeted spiritual assessment tool to guide them in addressing this (Reis et al., 2007).

Although past research has aimed to identify whether the integration of spiritual issues is desired in genetic counseling there has been little research on the methods in which this may be done. Furthermore, cancer genetic counseling has only rarely been

targeted in this research, despite many potential practice implications. The goal of this study was to learn more about what cancer genetic counseling patients want in terms of spiritual integration, and determine which methods would be most preferred.

2.3 Materials and Methods

2.3.1 Participants

A researcher-designed paper questionnaire was distributed to patients receiving cancer genetic counseling through Palmetto Health University of South Carolina Medical Group Genetic Counseling. Potential participants were invited to participate and received their questionnaire immediately following their appointment. Questionnaires were completed while the patient was at the clinic. All patients who underwent cancer genetic testing and were over the age of 18 were eligible for the study. Participation in this study was voluntary.

2.3.2 Research methods

This study took a quasi-experimental mixed methods approach to studying spirituality in cancer genetic counseling. The paper questionnaire was designed to assess patient perceptions of different methods of spiritual integration in genetic counseling. The first item asked participants about the importance of their personal spiritual beliefs. The second question asked the patient if they would like their genetic counselor to address spirituality in a genetic counseling appointment. The remaining eight items on this questionnaire described hypothetical scenarios with various methods of addressing spiritual views, requesting the participant to rate these as a positive or negative choice for the counselor. Several of these items were based on parts of the FICA and HOPE spiritual

assessment tools, and the Open Invite Mnemonic. The proposed actions by the genetic counselor included welcoming spiritual topics, asking about sources of meaning/comfort, asking patient about spirituality, asking about participation in spiritual communities, asking about spiritual practice, offering spiritual resources, sharing their own spiritual beliefs, and offering to pray with the patient. The quantitative questions were measured on a Likert scale measuring participant approval and disapproval.

The next section contained four open ended questions to gain more specific insight from each participant. These questions allowed patients to share their thoughts on the benefits of addressing spirituality in genetic counseling, the negatives of addressing spirituality in genetic counseling, the method of addressing spirituality in genetic counseling that is most appropriate, and an open ended inquiry requesting any other ways genetic counselors may address spirituality that were not included on the questionnaire. The questionnaire also included demographic information such as age, ethnicity, religious affiliation, sex, education level, and the reason for their genetic counseling appointment. The complete questionnaire is included in Appendix A.

2.3.3 Statistical Analysis and Statistical Methods

Statistical analysis for this study was performed using a mixed methods approach. The first two questionnaire items were compared to each other as well as the other Likert scale items using Spearman's Rho correlation. The demographic data were compared to all ten Likert scale via ANOVA analysis. In addition, frequency values and percentages were calculated for all Likert scale and demographic items. The questionnaire contained four open-ended questions. Thematic analysis methods were used to identify themes

within the open-ended questions. Frequency values were given for the themes identified through thematic analysis.

2.4 Results

2.4.1 Participant demographics

In total, 55 patients responded to the questionnaire, and 52 filled out the quantitative and demographic portions of the questionnaire completely. Three incomplete questionnaires were omitted from analysis due to insufficient data. Of the remaining 52 participants, 37 provided answers for qualitative questions. Participant demographics can be seen on Table 2.1.

2.4.2 Quantitative data

The results for the 10 Likert scale items overall did not demonstrate any statistically significant patterns. The mean, standard deviation, and percentage frequency values for each question can be seen in Table 2.2. The answers were coded numerically, such that 1=strongly disagree and 5=strongly agree. The participant group as a whole found spirituality to be important to their lives, based on the relatively high mean for the related questionnaire item. However, the overall trend about whether patients wanted genetic counselors to address these issues was ambiguous and had a relatively low mean.

Of note, 23.1% of patients felt that they would want genetic counselors to address their spiritual needs, while 48.1% indicated that they would not want this. The highest overall approval was observed for genetic counselors inviting a patient to discuss spirituality if they wish. The majority of participants, equaling 78.9% of the overall group, either approved or strongly approved of this method. In contrast, only 11.5%

disapproved. The questionnaire item relating to counselors asking about sources of meaning in a patient's life had similarly high approval. Overall, 67.3% of patients approved of this method, and only 7.7% disapproved. The method that showed the least overall approval was related to counselors sharing their own spiritual beliefs and experiences, which had 44.2% approval and 25% disapproval among the participant group. Figure 2.1 shows a rank-order representation of overall approval for each method, and Figure 2.2 shows the relative frequency of each answer for each questionnaire item.

Correlation analysis revealed a statistically significant relationship between the answers to the questionnaire item related to individuals' perceived importance of spiritual beliefs and most other quantitative questions. The exception to this was the item relating to a genetic counselor asking about sources of meaning and comfort in a patient's life. This indicates that individuals whose spiritual/religious beliefs are relatively important to them are more likely to want genetic counselors to address their spirituality and to view the majority of the related methods positively. However, the importance of one's spiritual beliefs did not seem to have a significant impact on their approval of genetic counselors asking about sources of meaning in one's life.

Another relationship that reached statistical significance is that Christians ranked their spiritual beliefs as being more important compared to Non-Christians ($p \leq .001$). Despite this relationship, there was only a statistically significant relationship between participant approval and religious affiliation for one method. Christian participants were significantly more likely to view a counselor sharing their own spiritual beliefs as a positive action in comparison to non-Christians, ($p=.038$). Two other methods showed associations between participant approval and religious affiliation that were nearly

statistically significant. These methods involved a genetic counselor asking a patient if they have spiritual views (p=.74), and asking a patient about their participation in religious/spiritual groups (p=.72). The p-values for all correlation analyses can be seen on Table 2.3. Figure 2.3 compares the mean answers between Christian and Non-Christian participants.

2.3.2 Qualitative data

A total of 37 of the 52 participants who completed the questionnaire answered at least one of the open-ended questions These questions allowed patients to provide more individualized thoughts and opinions about the integration of spirituality into cancer

individualized thoughts and opinions about the integration of spirituality into cancer genetic counseling. For each question, multiple themes arose among the answers. Not every answer matched a particular theme, however. The complete qualitative dataset and thematic analysis are included in Appendix B.

The first qualitative question explored what participants perceived as being the benefits of integrating spirituality into genetic counseling. Of the 37 patients in the qualitative dataset, 33 responded to this item. The responses were divided into six categories. The most common type of benefit that was recorded was positive effects on a patient's emotional well-being, such as "comfort" and "hope". Fourteen patients provided responses fitting this theme. One example of this theme reads:

> *I think one's beliefs affect the decisions that they make. These are tough decisions. I think spirituality provides comfort and hopefully peace after decisions are made.*

Four patients perceived that the main benefit of spirituality in genetic counseling was its ability to enhance the relationship between genetic counselors and their patients. Another four participants framed the benefits they would predict from spirituality in genetic counseling in the context their own religious beliefs. One individual wrote:

> *My spiritual beliefs, my faith in Christ are important to me. I can't imagine facing physical challenges such as a diagnosis of cancer without the knowledge and love of Christ.*

Not all respondents to this question indicated that they expected positives related to this concept, however. Three individuals indicated that they did not see any potential benefits at all. Another three participants felt uncertain about the benefits related to a genetic counselor addressing spirituality. Six participants noted that they did not think they would benefit from spirituality in genetic counseling, but acknowledged that others might. One such individual responded:

> *I don't feel that receiving counseling is that important to me. I am certain that it might help others by giving them comfort and a feeling of support.*

The second qualitative question was the opposite of the first, asking participants to indicate what the negatives associated with spirituality in genetic counseling might be. In total, 31 participants responded to this question. Compared to the previous item, there was less consensus among the themes seen in participants' responses. One group of four individuals indicated that spirituality may be an uncomfortable topic in this setting.

Similarly, five responses indicated a belief that spirituality is too personal to be discussed with a genetic counselor. One response that illustrates both of these themes reads:

> *Spiritual beliefs are a private matter. If one wishes to seek guidance after a genetic appointment they should seek their pastor or priest.*

Five participants noted that their main concern in terms of discussing spirituality with a genetic counselor was that they believe that this discussion would be out of place in this type of appointment. Others indicated that they were concerned that differing beliefs between the genetic counselor and the patient may harm the relationship between the two. This was observed in three responses. Finally, three participants described negatives from the context of their specific religious views. An example of this is:

> *I think sometimes people may be mad with God, especially when first learning about cancer, so it may make people unhappy.*

Some participants who responded to this question only saw positives associated with addressing spirituality. Eight responses did not note any potential negatives of spirituality in genetic counseling at all, while two indicated uncertainty regarding the question. Two participants indicated no drawbacks for themselves, but acknowledged that others could potentially have a negative reaction to this. An individual in the latter group wrote:

> *Possibly some. I can only see it as a negative if the person does not want religious counseling.*

The third qualitative question asked participants to indicate which method of addressing spirituality in genetic counseling was the most effective, in their opinion.

Twenty-one individuals responded to this item. These responses segregated into five categories communicating either a preferred spiritual care method or a perception that none of the methods are appropriate. One of the most frequent themes for this item included answers indicating no preference for a particular method, which was observed six times. These answers were difficult to interpret, since they were generally short and had multiple potential meanings. They could be understood either as a declaration that no method should be used, or an indication that they had no preference. The other common theme involved answers that showed preference for the genetic counselor asking prior permission or offering an invitation before discussing spirituality in genetic counseling. These answers reflect elements from the opening questions indicated in the FICA and HOPE spiritual assessment tools and the Open Invite Mnemonic. An example of this reads:

> *I prefer an initial discussion as to why the topic is being brought up. Then determinations by patient can be made.*

Two participants expressed that all methods are beneficial and should be encouraged, and another two claimed that they preferred prayer specifically. However, four individuals indicated that avoidance of spirituality in genetic counseling is the best option. One participant wrote:

> *I don't feel any are appropriate. If you need religious or spiritual guidance when dealing with health issues, you should go to your religious or spiritual place of worship.*

The final qualitative question asked participants to share their thoughts about any additional methods genetic counselors may use to address spirituality with their patients. The responses to this question did not necessarily answer the question directly, as many participants used this space simply to elaborate on their feelings about spirituality in genetic counseling in general. Twenty-three participants provided answers to this question, and the answers segregated into five themes. Nine participants simply responded that they did not have any additional thoughts to share. A group of five individuals provided answers proclaiming preference for counselors approaching the subject carefully, similarly to the previously discussed spiritual care tools. Four participants did not have additional suggestions, and instead provided indications that they approve of the methods provided. Another group comprising three individuals indicated that simply conveying respect towards patients' beliefs is an important approach for counselors to take. Finally, two individuals elaborated on their disapproval of spiritual discussions in genetic counseling by indicating that genetic counselors are not properly trained for this. One response reads:

> *In my opinion genetic counselors are not trained to discuss spiritual beliefs or convictions w/ those attending the facility. It is best not to go into this personal area.*

2.5 Discussion

2.5.1 Practice implications

The results show that addressing spirituality in cancer genetic counseling is a topic that shows a wide spectrum of patient opinions. As previous study has shown, it is

unlikely that there is one way of addressing spirituality in genetic counseling that all patients will approve of, even within a specific patient population (Thompson et al., 2015). There is a sizeable portion of genetic counseling patients that feel that having a genetic counselor address spirituality would be positive. However, other patients do not desire this, and may feel alienated or offended by more overt spiritual care methods. Unsurprisingly, this was heavily influenced by patients' own spiritual beliefs and the importance they attribute to them. Despite mixed opinions, every spiritual care method presented had an average approval rating that trended more towards the positive end of the scale. These results should not discourage genetic counselors from addressing spirituality with their patients, but instead indicate that they should take an individualized, nuanced approach when broaching the subject.

This study population seemed to show the highest overall approval for methods that addressed spiritual topics more indirectly. This supports the idea of approaching the subject lightly in ways similar to the open-invite mnemonic and HOPE tools, if a counselor perceives this as being appropriate (Saguil & Phelps, 2012). The highest approval was seen for a method even more hands-off than this mnemonic, and simply involves informing a patient that their spiritual beliefs are a welcome topic of discussion. Few participants opposed this method, making it a relatively benign option for genetic counselors to pursue. This method gives a patient control over the discussion, effectively asking permission and probing the need for further inquiry. The second highest approval was seen for the question that involves the counselor asking about sources of meaning and comfort in a patient's life. This is similar to one of the options presented in the first step of the HOPE spiritual assessment tool. Interestingly, there seemed to be a drop-off in

approval for the method related to the first step of the open invite mnemonic, conveyed by question five (Saguil & Phelps, 2012). This method involves counselors asking patients directly about their spiritual or religious beliefs. This may indicate that it is more appropriate in genetic counseling to take a cautious approach to spirituality when initially broaching the subject, since many participant responses indicate explicit information-gathering may be perceived as invasive or uncomfortable.

The two indirect approaches indicated have numerous advantages when applied to genetic counseling practice compared to other potential methods of addressing spirituality. Anderson (2009) found that genetic counseling patients in the prenatal setting needed to be welcomed to discuss spirituality in order to know that the topic was welcome. Both of the highest rated measures in this study are likely to accomplish this goal while minimizing potential negative effects. Some of these potential negative effects have been observed in this and previous studies, including being uncomfortable with the topic, perceiving spirituality as being out of place, and wanting to keep this information private (Thompson, 2012). Either welcoming a spiritual discussion or asking about sources of life meaning both give patients the choice to withhold any information they wish and avoid the subject entirely if they choose. Other barriers from the professional standpoint may be attenuated by this as well. Reis et al. (2007) notes insufficient time and a lack of training as main reasons that genetic counselors do not perform spiritual assessments regularly. These methodologies are simple ways of eliciting important information that need only involve a single statement and the use of the active listening skills genetic counselors are trained in, with a referral to trained experts if need be.

One finding that was somewhat unexpected was that the participant group had a relatively high approval rating towards a genetic counselor offering to pray with their patients. The question related to a genetic counselor offering to pray with patients had the third highest approval rating among our population, despite being one of the more personal and explicitly spiritual methods that was presented. Furthermore, two participants indicated that this was their preferred method of addressing spirituality in genetic counseling in the qualitative section. This illustrates how prayer can be a powerful and much desired tool for a counselor to serve their patient, although it should be approached carefully. It is difficult to tell from this study whether this was because of a perception of having differing beliefs or because prayer is more desired by Christians compared to other religious groups.

Surprisingly, the questionnaire item with the lowest average rating was related to participants' desire for genetic counselors to address their spiritual beliefs. In fact, this was the only question that had a negative average response. This seems somewhat discordant, since most other questions simply provided methods a counselor can use to accomplish this overall goal. It may be that this was because this question preceded the items related to methodology, such that individuals' initial interpretation of what a genetic counselor might do to address spiritual needs may be less palatable than the actual methods presented. This may also simply be a reflection of participants perceiving that they do not have spiritual "needs" but would not necessarily mind discussing spirituality with a genetic counselor. The purpose of a spiritual assessment is to illuminate spiritual needs that a patient may have identified themselves. Furthermore, definitions of spirituality vary greatly, and, similarly to healthcare providers, patients may

not have a concrete definition of what a spiritual need is (Saguil & Phelps, 2012). Perhaps the responses to this question may have differed if it was presented towards the end of the questionnaire.

Another potential explanation for the negative initial impression towards spirituality in genetic counseling relates to how the general public views the interplay between spirituality and genetics. Harris (2004) illustrated clearly that there is a persistent fear in many individuals that professionals working in genetics may be opposed to their worldview. For this reason, individuals with deeply held religious views may be suspicious of speaking with a genetic counselor about spirituality. Another study focused on professionals and clergy revealed that many members of both groups viewed science and religion as conflicting forces, rather than complementary. These individuals had much more difficulty identifying resources to help people who are struggling with issues that involve both faith and genetics (Bartlett & Johnson, 2009). The disconnect in public perception of the two concepts is further illustrated by themes observed in both this study and Thompson (2016), in which several patients indicated that religion and science should be kept separate. However, there is not enough concrete data to definitively show that this interpretation is truly applicable to this study.

2.5.2 Limitations

There were a number of factors in the study design that decreased the ability of this study to show significant trends. Patients were surveyed immediately following a cancer genetic counseling appointment so that they would have a clear recollection of what genetic counseling entailed. Although this likely led to more reliable responses from participants, it also made it so the participant group was relatively small and homogenous

in several aspects. Since a single clinic in South Carolina was utilized for data collection, participants were all from within a limited geographic range. This influenced demographic trends within the group and delays applicability of these results to patients in other areas. The vast majority of this group was female and identified as some form of Christian. Among non-Christian participants, most identified either as atheist, or as being spiritual but not religious. The ethnic makeup of the participant group was also limited to two primary groups: Caucasians and African Americans. Therefore, there are a great deal of religious and ethnic minority groups that are unrepresented in this sample. There may be correlations between demographic variables and patient perception of these methods that could not be seen simply because of the homogeneity of the sample.

In addition to demographic limitations, clinical logistics played a limiting role in this study as well. Due to the tight schedule within the clinic, many patients were unable to complete the questionnaire after their genetic counseling appointment and checking out from clinic, despite its relatively short length. Another limitation involved schedule slots that were appropriated to patients who either did not keep their appointment or did not undergo genetic testing.

2.5.3 Future directions

There are many future directions for research in this area. Performing a similar survey of patient perceptions of spiritual care methods in genetic counseling on a larger scale would be likely to reveal more significant trends and examine more demographic groups. Either a multi-center or online approach would suffice for this goal. Another potential area for study would be to survey cancer genetic counselors about their thoughts and feelings about these methods of addressing spirituality with their patients. Research

targeting specific populations about genetic counselors addressing spirituality could also lead to important practice implications. Certain religious and ethnic minorities may require different approaches to addressing spirituality in genetic counseling, and have disparate overall views on attempts to do so. It is vital to determine the role of counselors and patients having different spiritual beliefs on how patients react to discussions of spirituality. Finally, further research should be conducted to investigate if the public perceives genetics and spirituality to be incompatible, and what the cause of this stigma may be.

Table 2.1 Demographic data (n=52)

	# of Participants		# of Participants
Age		**Sex**	
<20	1	Male	2
20-30	7	Female	50
30-40	7	**Education Level**	
40-50	13	4-year degree	15
50-60	9	Grad./Professional degree	16
60-70	12	Some college	16
70-80	3	High School	5
Ethnicity		**Referral Indication**	
Non-Hispanic White	31	Family history	25
African American	18	Recent history	21
Mixed	2	Both	2
Religion		Cancer >1 year ago	1
Christian	44	Other	3
Non-Christian	8		

Table 2.2 Descriptive data for quantitative questions (Values are based on scale in which 1=Very negative and 5=Very Positive. GC=Genetic Counselor, n=52)

	Mean	SD	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)
Importance of spiritual beliefs	4.38	.889	1.9%	3.8%	3.8%	34.6%	55.8%
GCs should address spirituality	2.67	1.098	13.5%	34.6%	28.8%	17.3%	5.8%
GC offers invitation to discuss spirituality	3.98	.939	0%	11.5%	9.6%	48.1%	30.8%
GC asks about sources of meaning	3.88	.922	0%	7.7%	25.0%	38.5%	28.8%
GC asks if one has spiritual beliefs	3.52	1.111	5.8%	13.5%	21.2%	42.3%	17.3%
GC asks about religious/spiritual participation	3.48	1.038	3.8%	13.5%	28.8%	38.5%	15.4%
GC asks about spiritual practice	3.31	1.147	5.8%	21.2%	25.0%	32.7%	15.4%
GC offers spiritual resources	3.38	1.207	7.7%	15.4%	28.8%	26.9%	21.2%
GC shares own beliefs	3.29	1.177	7.7%	17.3%	30.8%	26.9%	17.3%
GC offers to pray together	3.58	1.289	11.5%	7.7%	19.2%	34.6%	26.9%

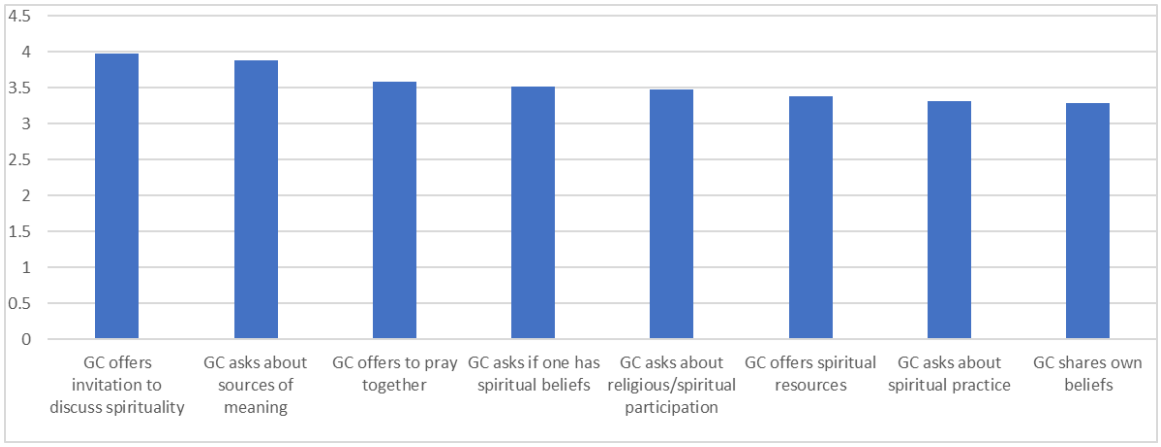

Figure 2.1 Rank-order bar graph depicting the mean value for questionnaire answers for each method (Rated on Likert scale such that 1=Very negative and 5=Very positive, n=52)

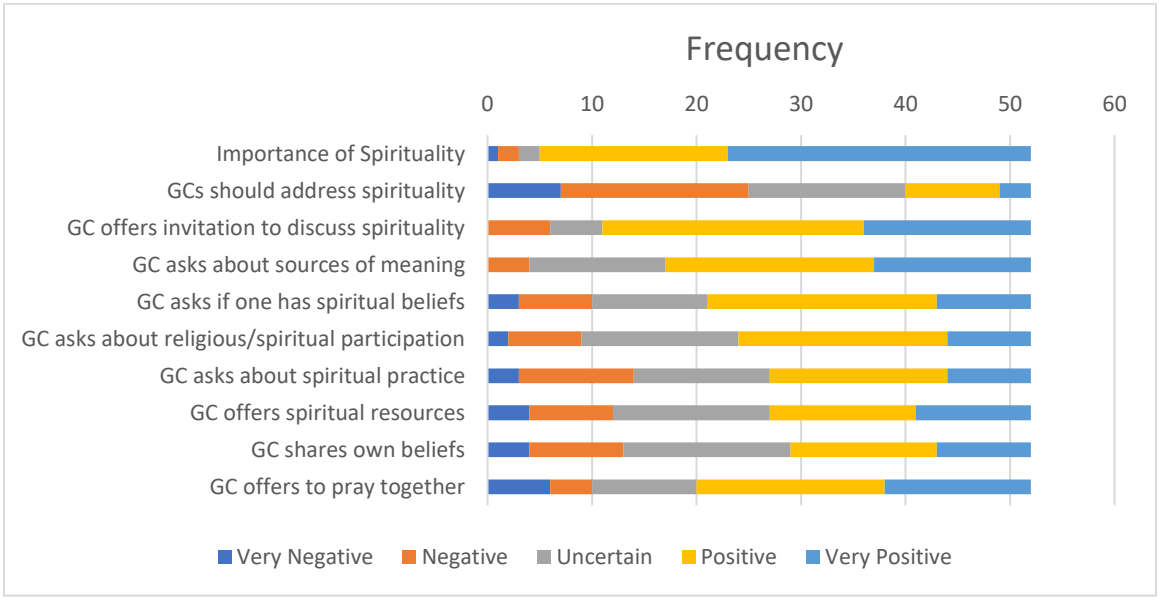

Figure 2.2 Segmented bar chart showing relative frequency for each answer type for questionnaire items (n=52)

Table 2.3 Correlation analysis data

	Importance of spiritual beliefs	**Christian vs. Non-Christian**
Importance of spiritual beliefs	N/a	**<.001**
GCs should address spirituality	**.001**	.409
GC offers invitation to discuss spirituality	**<.001**	.248
GC asks about sources of meaning	.052	.975
GC asks if one has spiritual beliefs	**.001**	.074
GC asks about religious/spiritual participation	**<.001**	.072
GC asks about spiritual practice	**.001**	.136
GC offers spiritual resources	**.022**	.332
GC shares own beliefs	**<.001**	**.038**
GC offers to pray together	**.001**	.171

Data represents p-values for relationships between two variables. Statistically significant if p-value<.05.

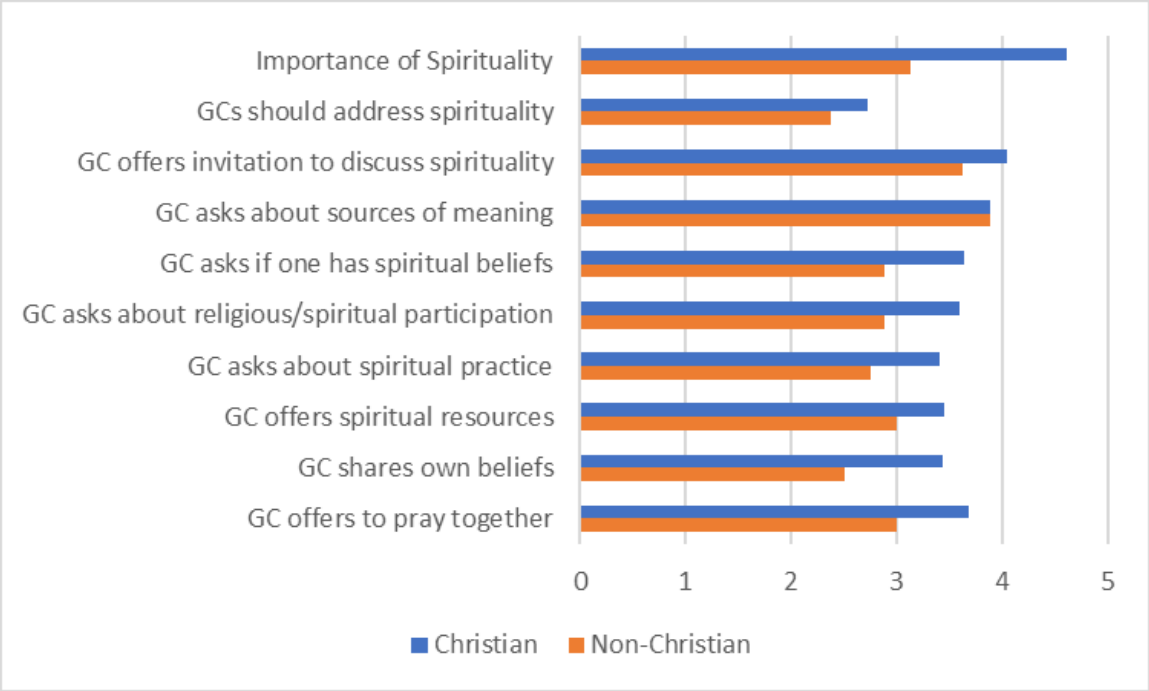

Figure 2.3 Comparison between Christian and Non-Christian regarding mean answers for each questionnaire item. (Questionnaire answers ranked on Likert scale where 1=Very negative and 5=Very positive, n=52)

Chapter 3

Conclusions

[1]Spencer, C. M., Edwards, J., DeGregory, C., Brooks, K. (2018). Spiritual assessment in genetic counseling: Patient perception of methods. *Journal of Genetic Counseling*. To be submitted.

Spirituality is an inherently difficult topic to make definitive statements about, due to the wide spectrum of belief systems that individuals hold. However, due to the massive influence that spiritual beliefs may have on a person's life in the context of disease, they should not be ignored or considered irrelevant to medical care. This study cannot definitively recommend a single approach to addressing spirituality with cancer genetic counseling patients, nor can it suggest that any one method should be implemented in every session. However, the results of this study should empower cancer genetic counselors to explore spirituality with a patient if they feel that it is appropriate and beneficial. Many patients tend to view methods related to this to be positive, and more cautious approaches tend to mitigate potentially negative consequences of attempting this. Genetic counselors working with highly spiritual populations may benefit from familiarizing themselves with spiritual assessment tools such as FICA, HOPE, and the Open Invite Mnemonic. Although implementing these tools in their entirety may not always be appropriate for genetic counseling, learning about them may help guide them through the process should spiritual issues arise in patient sessions. More research should be conducted to elucidate the applicability of different spiritual care methods in genetic counseling in different situations and populations.

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Appendix A: Questionnaire Tool

Please select your level of agreement or rate your reaction for each of the following statements. ***When answering, think like the counselor is performing these actions in a way that addresses your concerns about cancer.***

1. My religious/spiritual beliefs are important to me.
   ☐ Strongly agree ☐ Agree ☐ Uncertain ☐ Disagree ☐ Strongly disagree

2. I would like my genetic counselor to address my religious/spiritual needs in some way.
   ☐ Strongly agree ☐ Agree ☐ Uncertain ☐ Disagree ☐ Strongly disagree

3. Your genetic counselor **tells you that spiritual/religious topics are welcome** in the appointment if you wish to speak about them. You view this action by the counselor as
   ☐ Very Positive ☐ Positive ☐ Uncertain ☐ Negative ☐ Very Negative

4. Your genetic counselor **asks you about the sources of meaning and comfort in your life**. You view this action by the counselor as
   ☐ Very Positive ☐ Positive ☐ Uncertain ☐ Negative ☐ Very Negative

5. Your genetic counselor directly **asks if you hold spiritual or religious beliefs**. You view this action by the counselor as
   ☐ Very Positive ☐ Positive ☐ Uncertain ☐ Negative ☐ Very Negative

6. Following your response to the question in #5, your genetic counselor **asks you whether you participate in any organized religious/spiritual communities**. You view this action by the counselor as
   ☐ Very Positive ☐ Positive ☐ Uncertain ☐ Negative ☐ Very Negative

7. Following your response to the question in #5, your genetic counselor **asks you how you practice your personal religious/spiritual beliefs**. You view this action by the counselor as
   ☐ Very Positive ☐ Positive ☐ Uncertain ☐ Negative ☐ Very Negative

8. After you and your genetic counselor have had some discussion about religion/spirituality, your counselor **offers you spiritual/religious resources** to aid you outside of the appointment. You view this action by the counselor as
   ☐ Very Positive ☐ Positive ☐ Uncertain ☐ Negative ☐ Very Negative

9. In this discussion, your genetic counselor **shares his/her own spiritual beliefs and experiences**. You view this action by the counselor as
   ☐ Very Positive ☐ Positive ☐ Uncertain ☐ Negative ☐ Very Negative

10. In this discussion, your genetic counselor **offers to pray with you**, according to your personal beliefs (regardless of the counselor's beliefs). You view this action by the counselor as
    ☐ Very Positive ☐ Positive ☐ Uncertain ☐ Negative ☐ Very Negative

For questions 11-14, please record your thoughts. You may choose to leave any or all of these blank.

11. What **potential benefits** do you think are gained with addressing spirituality/religion in genetic counseling? If you do not see any benefits for yourself, do you think it can help other people? How?

12. What **potential negatives** do you think are gained with addressing spirituality/religion in genetic counseling? If you do not see any negatives for yourself, do you think it can have negative consequences for others? How?

13. Which of the methods described, if any, do you feel is most appropriate for genetic counseling?

14. Can you think of any other ways that genetic counselors can meet their patients' spiritual needs, or respect those who do not have spiritual needs?

Demographics: Circle your choices

Age: <20 20-30 30-40 40-50 50-60 60-70 70-80 80+

Ethnicity: Non-Hispanic White African-American Asian/Pacific Islander Hispanic Native American Other:_____

Religion: Protestant Catholic Jewish Muslim Mormon Agnostic Atheist Hindu Christian-other Not sure Spiritual but not Religious Other:_____

Sex: Male Female

Education Level: Never attended High School Some High School High School Diploma/GED Some college/2 year degree Undergraduate/4-year degree Graduate/Professional degree

Reason for Counseling: Recent Cancer diagnosis (within last year) Cancer diagnosis more than one year ago Family history of cancer Other:_____

Dear Participant,

My name is Christopher Spencer and I am a student at the Genetic Counseling Program at the University of South Carolina. For my thesis research, I am investigating the role of religious/spiritual beliefs in cancer genetic counseling. Since you have recently undergone genetic counseling at Palmetto Health USC Medical Group Genetic Counseling Services, I am inviting you to participate in this study by completing the attached questionnaire. This will require roughly 5-10 minutes to complete. There is no compensation for responding, nor is there any known risk. In order to ensure that all information will remain confidential, please *do not* include your name. If you choose to participate in this project, please answer all questions as honestly as possible and return the completed questionnaire promptly to the appropriate staff at Palmetto Health USC Medical Group Genetic Counseling Services. Participation is strictly voluntary and you may refuse to participate at any time.

Thank you for taking the time to assist me in my research endeavors. The data collected will provide useful information on spirituality that may help to refine genetic counseling services. This study is designed not only to provide data on the spiritual needs of patients and how they may be addressed, but also protect those without strong spiritual needs from discomfort. Completion and return of the questionnaire will indicate your willingness to participate in this study. If you require additional information or have questions, please contact me at the number listed below.

This study is meant to be non-discriminatory, and input is greatly appreciated from all participants regardless of their beliefs, or lack thereof. If you are not satisfied with the manner in which this study is being conducted, you may report (anonymously, if you so choose) any complaints to the director of the University of South Carolina Genetic Counseling Program, Professor Janice Edwards, at Janice.Edwards@uscmed.sc.edu.

Sincerely,

Christopher Spencer
(434)770-1887
Christopher.Spencer@uscmed.sc.edu

Appendix B: Qualitative Thematic Analysis

Participant #	**Responses**	**Themes**
1	**Question 11** *Cater to everyone and what is important to them* **Question 12** *Too personal if not addressed correctly* **Question 13** No answer **Question 14** No answer	**Question 11** Improved patient/counselor relationship **Question 12** Privacy concerns **Question 13** **Question 14**
2	**Question 11** *Uncertain* **Question 12** *Making people uncomfortable* **Question 13** No answer	**Question 11** Unsure **Question 12** Perception as uncomfortable topic **Question 13**

2 cont.	**Question 14** *No*	**Question 14** None
3	**Question 11** *As a person that is not religious, I feel as though it is constantly being shoved down my throat. I can see how it might be comforting to those who are.* **Question 12** *I personally would be annoyed and my not care to talk to that doctor.* **Question 13** *None* **Question 14** No answer	**Question 11** Negative w/ some benefits for others **Question 12** No fitting theme **Question 13** None **Question 14**
4	**Question 11** *Spiritual wellness improves mental wellness as well as physical wellness*	**Question 11** Enhanced emotional well-being

4 (cont.)	**Question 12** *I don't think there are any negative consequences of addressing spirituality* **Question 13** No answer **Question 14** No answer	**Question 12** No negatives **Question 13** **Question 14**
5	**Question 11** *Maybe for people that have spiritual beliefs this would be helpful. I, however, do not have these beliefs so nothing would be gained* **Question 12** *Spiritual beliefs are a private matter. If one wishes to seek guidance after a genetic appointment they should seek their pastor or priest*	**Question 11** No benefits for self, some for others **Question 12** Perception as uncomfortable topic, privacy concerns

5 (cont.)	**Question 13** *I believe keeping genetic counseling strictly science based is for the best* **Question 14** No answer	**Question 13** Avoidance of spirituality **Question 14**
6	**Question 11** *I don't think addressing spirituality is necessary* **Question 12** *Some may feel uncomfortable* **Question 13** *Leaving it undiscussed and private* **Question 14** *None*	**Question 11** No benefits **Question 12** Perception as uncomfortable topic **Question 13** Avoidance of spirituality **Question 14** None
7	**Question 11** *Benefits include understanding of higher power having last word in all things. Even though it's good to have this information.*	**Question 11** Religious justification

7 (cont.)	**Question 12** *Confusion of reasoning for conversation in this setting (out of the blue)* **Question 13** *None* **Question 14** *None*	**Question 12** Topic is out of place **Question 13** None **Question 14** None
8	**Question 11** *I think being empathetic rather than sympathetic is helpful. It brings the provider down to the patient's level. You can relate, even if different religions.* **Question 12** *Some people may not be religious, and not like someone else asking.*	**Question 11** Improved patient/counselor relationship **Question 12** Differing beliefs as a barrier

8 (cont.)	**Question 13** *I think asking if someone is religious is better, then building on their answer would benefit many patients* **Question 14** No answer	**Question 13** GC offers invite/gets permission **Question 14**
9	**Question 11** *Comfort level* **Question 12** *I don't' think it's bad.* **Question 13** *I think its one on one basic knowledge if they care to see about it* **Question 14** *Just make it known if someone is asking*	**Question 11** Enhanced emotional well-being **Question 12** No negatives **Question 13** GC offers invite/gets permission **Question 14** GC offers invite/gets permission
10		

10 (cont.)	**Question 11** *It wouldn't at all benefit me, but it may benefit others. It could possibly comfort them, though it may give them false hope* **Question 12** *I don't believe spirituality or religion should be involved with scientific inquiry* **Question 13** *I don't feel any are appropriate. If you need reliious or spiritual guidance when dealing with health issues, you should go to your religious or spiritual place of worship* **Question 14** No answer	**Question 11** No benefits for self, some for others **Question 12** Topic is out of place **Question 13** Avoidance of spirituality **Question 14**
11		

11 (cont.)	**Question 11** *I believe it allows the counselor to know your expectations and help you make the best well informed decision* **Question 12** *None* **Question 13** *All are important* **Question 14** *They are doing great*	**Question 11** Improved patient/counselor relationship **Question 12** No negatives **Question 13** All methods **Question 14** Positive impression of spiritual care
12	**Question 11** *Comfort and peace* **Question 12** *None* **Question 13** No answer **Question 14** *No*	**Question 11** Enhanced emotional well-being **Question 12** No negatives **Question 13** **Question 14** None
13		

13 (cont.)	**Question 11** *It gives and helps other individuals who might be going through and they may not know the Lord as their personal savior. God always sends a messenger* **Question 12** *None* **Question 13** *Spirituality* **Question 14** *Maybe pamphlets*	**Question 11** Religious justification **Question 12** No negatives **Question 13** No theme **Question 14** No theme
14	**Question 11** *I know that God put people/places in place for me getting my mammogram, for my surgery, size of my tumor, my treatment, my doctors. He had his hand in my life during this whole process that I have gone through*	**Question 11** Religious justification

14 (cont.)	**Question 12** *Personally I see no negative because God will take care of you* **Question 13** No answer **Question 14** *I think that covered the topics*	**Question 12** No negatives **Question 13** **Question 14** Positive impression of spiritual care
15	**Question 11** *I don't see any benefits* **Question 12** No answer **Question 13** No answer **Question 14** No answer	**Question 11** No benefits **Question 12** **Question 13** **Question 14**
16	**Question 11** *Prayer gives hope*	**Question 11** Enhanced emotional well-being

16 (cont.)	**Question 12** *Everyone does not agree with prayer* **Question 13** *Just prayer* **Question 14** *No*	**Question 12** Differing beliefs as a barrier **Question 13** Prayer **Question 14** None
17	**Question 11** *It gives the patient and doctor a better relationship, especially if religion is in common* **Question 12** *No negatives for myself, but people who do not want to share this be negative* **Question 13** *N/a* **Question 14** *No*	**Question 11** Improved patient/counselor relationship **Question 12** No negatives for self, some for others **Question 13** **Question 14** None
18	**Question 11** No answer	**Question 11**

18 (cont.)	**Question 12** *A patient's religious beliefs are personal and beyond the scope of medical counseling* **Question 13** No answer **Question 14** No answer	**Question 12** Privacy concerns **Question 13** **Question 14**
19	**Question 11** *Maybe an offer to discuss it if the client wants to. If not, don't do it* **Question 12** *It would not be something I would deem necessary or expected* **Question 13** No answer **Question 14** *Just respect the person for who they are*	**Question 11** No benefits for self, some for others **Question 12** Topic is out of place **Question 13** **Question 14** Respect individuals
20		

20 (cont.)	**Question 11** *No potential benefits* **Question 12** No answer **Question 13** No answer **Question 14** No answer	**Question 11** No benefits **Question 12** **Question 13** **Question 14**
21	**Question 11** *I think one's beliefs affect the decisions that they make. These are tough decisions. I think spirituality provides comfort and hopefully peace after decisions are made* **Question 12** *Someone could hold beliefs that are totally the opposite of your beliefs. This may cause more stress.*	**Question 11** Enhanced emotional well-being **Question 12** Differing beliefs as a barrier

21 (cont.)	**Question 13** *I think if a counselor realizes their beliefs are different and can approach patient from the beliefs they may hold in common, it could be a really good thing. If not, I think great harm could be done.* **Question 14** *Maybe inquiring about patients' spiritual dependence (how important is spirituality to you) and go from there*	**Question 13** No theme **Question 14** GC offers invite/gets permission
22	**Question 11** *I don't feel that receiving counseling is that important to me. I am certain that it might help others by giving them comfort and a feeling of support*	**Question 11** No benefits for self, some for others. Enhanced emotional well-being

22 (cont.)	**Question 12** *Possibly some. I can only see it as a negative if the person does not want religious counseling.* **Question 13** *If the person wants counseling, it is appropriate* **Question 14** *No*	**Question 12** No negatives for self, some for others **Question 13** GC offers invite/gets permission **Question 14** None
23	**Question 11** *If anything it gives me comfort* **Question 12** No answer **Question 13** No answer **Question 14** *Just ask the patient if they have any spiritual needs, at least that opens up the floor for conversation.*	**Question 11** Enhanced emotional well-being **Question 12** **Question 13** **Question 14** GC offers invite/gets permission

24	**Question 11** *Power of positive thinking whether spiritually or religiously determines a person's view on positive treatment* **Question 12** *Question whether genetic genetic counseling is in accordance with God's religious views* **Question 13** No answer **Question 14** *Compassion without judgement of religious views*	**Question 11** Enhanced emotional well-being **Question 12** Conflict with religious beliefs **Question 13** **Question 14** Respect individuals
25	**Question 11** No answer **Question 12** No answer **Question 13** *None*	**Question 11** **Question 12** **Question 13** None

25 (cont.)	**Question 14** *No*	**Question 14** None
26	**Question 11** No answer **Question 12** No answer **Question 13** No answer **Question 14** *All good*	**Question 11** **Question 12** **Question 13** None **Question 14** Positive impression of spiritual care
27	**Question 11** *My spiritual beliefs, my faith in Christ are important to me. I can't imagine facing physical challenges such as a diagnosis of cancer without the knowledge and love of Christ* **Question 12** No answer	**Question 11** Religious justification **Question 12**

27 (cont.)	**Question 13** No answer **Question 14** No answer	**Question 13** **Question 14**
28	**Question 11** *For patients that are undergoing testing for cancer genes or other genetic problems having someone validate your religious beliefs would put you at ease.* **Question 12** *Some people may not be comfortable starting their beliefs* **Question 13** *I feel like all are reasonable* **Question 14** *I think for validating their feelings is awesome*	**Question 11** Enhanced emotional well-being **Question 12** Perception as uncomfortable topic **Question 13** All methods **Question 14** Positive impression of spiritual care
29		

29 (cont.)	**Question 11** *Comfort from finding out bad information.* **Question 12** *It goes away from the main idea of genetics which is why talking to a genetics counselor* **Question 13** No answer **Question 14** No answer	**Question 11** Enhanced emotional well-being **Question 12** Topic is out of place **Question 13** **Question 14**
30	**Question 11** *None for me. It could be positive for others* **Question 12** No answer **Question 13** *None*	**Question 11** No benefits for self, some for others **Question 12** **Question 13** None

30 (cont.)	**Question 14** *Ask if a client wishes to discuss.*	**Question 14** GC offers invite/gets permission
31	**Question 11** No answer **Question 12** No answer **Question 13** No answer **Question 14** *Each individual should choose the person to share spiritual needs with. My choce is someone who pursues the ministry, not genetics*	**Question 11** **Question 12** **Question 13** **Question 14** Genetic counselors aren't trained
32	**Question 11** *I think it helps the counselor better understand the patient.* **Question 12** No answer	**Question 11** Improved patient/counselor relationship **Question 12**

32 (cont.)	**Question 13** No answer **Question 14** *Not really, but showing respect for the patient's beliefs is very important*	**Question 13** **Question 14** Respect individuals
33	**Question 11** *Uplifting. Cancer is very scary and when I think of God, it makes me smile and be positive and happy.* **Question 12** *I think sometimes people may be mad with God especially when first learning about cancer so it may make people unhappy* **Question 13** *Offering spiritual resources and praying with me.* **Question 14** No answer	**Question 11** Enhanced emotional well-being **Question 12** Conflict with religious beliefs **Question 13** Prayer **Question 14**
34		

34 (cont.)	**Question 11** *Good benefit if welcomed by the participant* **Question 12** *Negative consequences limited if genetic counseling gets permission to address this discussion* **Question 13** *Most appropriate would be non discussion of spiritual beliefs* **Question 14** *In my opinion, genetic counselors are not trained to discuss spiritual beliefs or convictions w/ those attending the facility. It is best not to go into this personal area.*	**Question 11** Enhanced emotional well-being **Question 12** No negatives **Question 13** Avoidance of spirituality **Question 14** Genetic counselors aren't trained
35	**Question 11** *I have no thoughts or issues with this topic*	**Question 11** Unsure

35 (cont.)	**Question 12** *Not sure* **Question 13** *None of the above* **Question 14** *I can not*	**Question 12** Unsure **Question 13** None **Question 14** None
36	**Question 11** *Comfort in knowing I can express mine and that it impacts care.* **Question 12** *Would not want counselor to try to sway opinion* **Question 13** *To ask the question if counselor would like to discuss* **Question 14** No answer	**Question 11** Enhanced emotional well-being **Question 12** Conflict with religious beliefs **Question 13** Genetic counselor offers invite/gets permission **Question 14**
37		

37 (cont.)	**Question 11** *Mainly, benefits are gained if spirituality/religion is important to the patient with respect to cancer (during consult or results time). Could offer this discussion/topic to patient with explanation as to why.* **Question 12** *Some people do not feel that religious preferences are pertinent at initial stages of testing* **Question 13** *I prefer an initial discussion is to why the topic is being brought up. Then determinations by patient can be made.* **Question 14** *See above*	**Question 11** Enhanced emotional well-being **Question 12** Topic is out of place **Question 13** Genetic counselor offers invite/gets permission **Question 14** Genetic counselor offers invite/gets permission