The Utilization of Healthcare Chaplains by Genetic Counselors

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THE UTILIZATION OF HEALTHCARE CHAPLAINS BY GENETIC COUNSELORS

By

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ABSTRACT

Healthcare chaplains prioritize the spiritual and religious care a patient and their family may need during their healthcare experience. This study investigated the current utilization of healthcare chaplains by genetic counselors, as well as the ability, in time and skill, of the healthcare chaplains to see genetic counseling patients. Lastly, the study investigated if genetic counseling patients would accept a referral to meet with a healthcare chaplain. We hypothesized that genetic counselors are not utilizing healthcare chaplains, healthcare chaplains have the ability to see genetic counseling patients, and genetic counseling patients would consider meeting with a healthcare chaplain.

This study distributed an original electronic questionnaire to healthcare chaplains. An ancillary, original, electronic and paper/printed questionnaire was distributed to prenatal, pediatric, and cancer genetic counseling patients at Prisma Health – Midlands and The Greenwood Genetic Center, Greenwood campus. A mixture of percentages and frequencies were calculated as well as themes through a content analysis approach.

Data was collected from 253 healthcare chaplains (57.1% female; 41.6% male) and 110 genetic counseling patients (37.3% cancer; 9.1% general; 12.7% pediatric; 40.9% prenatal). Only 15.45% of healthcare chaplains claimed that a genetic counselor had referred a patient to them. More than 60% of healthcare chaplains felt comfortable, very comfortable, or extremely comfortable while discussing genetic syndromes or cancer susceptibility genes with patients and over 70% felt comfortable, very comfortable, or extremely comfortable with basic genetic concepts and medical
terminology. Lastly, around 45% of genetic counseling patients stated they would consider meeting with a healthcare chaplain.

Healthcare chaplains feel comfortable in their knowledge and skill to meet with genetic counseling patients but are not currently being widely used by genetic counselors as a referral. Genetic counselors should consider referring select patients who may be experiencing spiritual distress to healthcare chaplains.
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CHAPTER 1: BACKGROUND

1.1 Background

1.1.1 Spiritual Care

As defined by Roze des Ordones et al. (2020), “spirituality is a dynamic and intrinsic way in which we seek meaning, purpose, and transcendence” and “spiritual distress is the overwhelming sense of unrelieved suffering that happens when a person’s sense of meaning, purpose, connection, hope, or identity becomes acutely more vulnerable or is challenged”. Physical manifestations, such as disease progression, failed treatments, and symptoms such as pain and fatigue, have been associated with spiritual distress (Roze des Ordones et al., 2018). Similarly, spiritual well-being has been found to be negatively correlated with depression and anxiety (Kandasamy et al., 2011). For these reasons, managing spiritual distress in a healthcare setting may be beneficial to patients and their providers. Managing spiritual distress can be achieved through different approaches for different patients. For example, many African Americans turn to the Bible and prayer during times of illness and stressful life events (Hamilton et al., 2013, 2020). Similarly, many ICU patients want their spiritual needs to be assessed and fathers of ill-infants want to discuss spirituality to help with their lack of control in the situation (Gordon et al., 2018). Individuals that are not experiencing spiritual distress may also benefit from spiritual support in a healthcare setting. Spiritual support, or spiritual care, may consist of religious practices, such as prayer, spiritual conversations around meaning, purpose, and hope, reflection, different counseling interventions, emotional
support through empathy, or advocacy for the patient and their family (Roze des Ordones et al., 2020).

Many healthcare providers run into the challenge of how to deliver spiritual care to their patients (Peteet & Balboni, 2013). Barriers to providing spiritual care to patients include lack of time, inadequate training, lack of privacy, and the thought that spiritual care would be better offered by others (Balboni et al., 2014). Genetic counselors have revealed that they sometimes avoid spiritual discussions with patients because of a lack of training, lack of time, and fear of not properly addressing the patients’ spiritual concerns (Reis et al., 2007). This study aimed to examine if genetic counselors are currently, and should be, utilizing healthcare chaplains as a way to deliver spiritual care to all patients in need or distress.

1.1.2 Genetic Counselors’ Scope of Practice

The National Society of Genetic Counselors defines genetic counseling as:

The process of helping people understand and adapt to the medical, psychological, and familial implications of the genetic contributions to disease.

This process integrates:

- Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence
- Education about inheritance, testing, management, prevention, resources, and research.
- Counseling to promote informed choices and adaptation to the risk or condition. (Resta et al., 2006)
In addition, all genetic counselors should be able to demonstrate 22 practice-based competencies described by the Accreditation Council for Genetic Counseling. All 22 competencies fall under one of four domains: genetics expertise and analysis; interpersonal, psychosocial, and counseling skills; education; and professional development & practice (Accreditation Council for Genetic Counseling, 2019).

Genetic counselors are trained to be aware of patients’ religious and spiritual beliefs. One practice-based competency, under the education domain, describes the ability to “identify factors that affect the learning process such as intellectual disability, emotional state, socioeconomic factors, physical abilities, religious and cultural beliefs, motivation, language and educational background” (Accreditation Council for Genetic Counseling, 2019).

The National Society of Genetic Counseling Code of Ethics (2017) states that genetic counselors work to “respect their clients’ beliefs, inclinations, circumstances, feelings, family relationships, sexual orientation, religion, gender identity, and cultural traditions.” However, genetic counselors are trained to “work within their scope of professional practice and recognize the limits of their own knowledge, expertise, and competence,” as stated by the National Society of Genetic Counseling Code of Ethics (2017). These guidelines allow genetic counselors to evaluate their own scope of practice and limits of their knowledge. When training genetic counseling students how to address religion and spirituality in clinical practice, North American programs rely on writing assignments, class exercises, and role plays to introduce students to religious and spiritual topics (Murray et al., 2020). Due to a lack of standardization in this curriculum, as well as a lack of strict scope of practice guidelines, genetic counseling students and practicing
genetic counselors are left to decide their own involvement in spiritual and religious conversations with their patients.

1.1.3 Genetic Counseling Specialties

Genetic counseling is present in almost every medical specialty, and the role of a genetic counselor slightly differs between each specialty (Abacan et al., 2019). Genetic counselors can specialize in prenatal, pediatrics, oncology, neurology, psychiatry, and many more areas (National Society of Genetic Counselors, n.d.). Along with the services genetic counselors provide to patients, spiritual care may be needed for many genetic counseling patients. For example, a literature review by Wiener et al. (2013) found that faith is important to parents of children receiving pediatric palliative care. Faith can “provide guidance, make sense of their situation, grant permission around end-of-life decision making, and to better cope” (Wiener et al., 2013). Similarly, cancer patients have indicated a desire for help with their spiritual needs and have shown that spiritual care can correlate with “better satisfaction with care, QOL (quality of life), psychological and spiritual adjustment, and less aggressive care at the end of life (EOL), as well as with attendant lower EOL costs, particularly among racial/ethnic minorities and high religious coping patients” (Peteet & Balboni, 2013).

1.1.4 Genetic Counseling and Spirituality

Research aimed at defining the scope of practice of healthcare providers and genetic counselors when discussing religion and spirituality has had contradictory results. Some patients wished healthcare professionals would open the door to conversations about faith so they did not have to (Scully et al., 2017). However, when specifically considering genetic counselors, other patients did not believe a genetic counselor should
bring up religion or spirituality in a session because they are not as qualified as others (Thompson et al., 2016). Thus, the debate surrounding whether or not genetic counselors should initiate conversations regarding religious and spiritual topics with their patients remains unsettled.

Genetic counselors have a unique healthcare role as they are trained in professional guidance and compassion (Accreditation Council for Genetic Counseling, 2019). Modell et al. (2019) proposed that scientists and religious leaders approach conversations regarding genetic testing from different perspectives. They claim that scientists emphasized professional guidance while religious leaders emphasized compassion and family needs (Modell et al., 2019). As a trained professional in both of these areas, genetic counselors may be the key to connecting patients with spiritual guidance resources.

1.1.5 Religious Leaders’ Influence on Patients

A similar conversation is being had to determine the scope of practice of clergy members and religious leaders when discussing genetics, genetic counseling, and medical decision-making. Patients that wished healthcare workers would be more open about faith believed that their faith organizations could not provide pastoral care in regard to their medical decisions. This was because the patients perceived a lack of knowledge in genetics from their faith organization members (Scully et al., 2017). Similarly, individuals faced with the decision to terminate pregnancies affected with sickle cell disorders and thalassemia major believed religious leaders played an insignificant role in their decision-making process (Ahmed et al., 2006).
Lemons et al. (2013) showed that clergy members have limited knowledge in genetics and genetic counseling, although they have counseled members of their congregation regarding genetic testing. When asked to provide hypothetical genetic information to congregants, clergy members often provided inaccurate information. Similarly, when asked why a couple would receive genetic testing, some clergy members answered for homosexuality, cloning, and sickle cell anemia (Lemons et al., 2013).

Despite certain individuals' hesitancy, some patients benefit from their spiritual organizations’ discussions about medical care, leading them to seek out interventions from their spiritual leaders (Daniels et al., 2007; Price et al., 2009). Similarly, religious leaders, specifically Orthodox Jewish thought leaders, have played a significant role in encouraging their congregation to utilize genetic services and testing (Bressler & Popp, 2017). Individuals of Ashkenazi Jewish descent have about a 1 in 4 chance to be a carrier of a rare genetic disorder (Gross et al., 2008). According to Gross et al. (2008), due to this risk, a resolution urging all Reform Rabbis to counsel potential couples on genetic testing was passed. A study surrounding a novel genetic screening program in Atlanta for individuals of Ashkenazi Jewish descent reported that rabbis and synagogues were one of the top three sources that individuals found out about the program (Shao et al., 2015).

Although clergy members and religious leaders that do not work as healthcare chaplains serve their congregation in many ways, they may not be the best at providing guidance during a medical crisis and facilitating medical decision-making. Lemons et al. (2013) suggested that genetic counselors should work closely with hospital chaplains in order to assess religious and spiritual conversations with patients.
1.1.6 Healthcare Chaplaincy

The Association of Professional Chaplains et al. (2001) states:

Professional chaplains offer spiritual care to all who are in need and have specialized education to mobilize spiritual resources so that patients cope more effectively. They maintain confidentiality and provide a supportive context within which patients can discuss their concerns.

Chaplains have the ability to work in many different settings. Specifically, healthcare chaplains prioritize the spiritual and religious care a patient and their family may need during their healthcare experience. Healthcare chaplains may spend as little as five minutes with patients or up to three hours with patients. Anywhere from 40% to 60% of healthcare chaplain visits are an initial meeting between the patient and the healthcare chaplain. Spiritual and religious interventions do not occur with every interaction between a healthcare chaplain and a patient (Timmins et al., 2018).

There are 70 Chaplaincy training programs found within the Association of Theological Schools (ATS) and over a dozen schools that are interfaith institutions. The gold standard for education is advanced theological training in combination with clinical training by certified educators trained in clinical pastoral education. The number of completed units of clinical pastoral education, or CPE, has grown over the years (Cadge et al., 2020). For one certifying board, the Board of Chaplaincy Certification, Inc., a board-certified chaplain must first have a graduate degree in theology (or its equivalent), four units of CPE (1600 hours), endorsement of a faith group, and 2000 hours of work experience (Cadge et al., 2019).
Healthcare chaplains are trained to serve all faith groups, provide care through listening, serve on a patient care team, and provide guidance in the healthcare system (Association of Professional Chaplains et al., 2001). Educators of chaplains emphasize teaching the importance of working in a multifaith environment, using theological skills and knowledge to address suffering, and the identity and authority of the chaplain to their patients (Cadge et al., 2020). During times of illness and stress, people may turn to spiritual resources for guidance and help. Chaplains play a role in “identifying patients in spiritual distress and helping them resolve their religious or spiritual problems, thus improving their health and adjustment” (Association of Professional Chaplains et al., 2001).

1.1.7 Healthcare Chaplaincy Referrals

Poncin et al. (2020) identified many motivators of referrals to healthcare chaplains from healthcare workers, including difficulties in the patient-professional relationship, supporting patients, understanding patients, and spiritual care. Statements from healthcare workers such as, “this lady is aggressive and may be stressed,” “this patient […] is quite guarded,” and “I find her too positive” have led to referrals to a healthcare chaplain in hopes of facilitating conversation between the patient and healthcare worker. Similar statements from healthcare workers such as “it would do her good to talk to you” and “I wonder why, what she’s expecting from us” have led to referrals to a healthcare chaplain in hopes to support and better understand the patient. Healthcare professionals do not always associate spiritual care with religion – they also view spiritual care as an approach “to access patients’ sense of identity, as well as the
meaning they give to their lives and experiences, by enabling patients to talk and listening to them” (Poncin et al., 2020).

Spiritual assessments are tools that can be helpful to healthcare professionals when deciding whether or not a patient needs a healthcare chaplain referral (Piotrowski, 2013). Three examples of spiritual assessment tools that healthcare providers utilize are FICA, SPIRIT, and HOPE. The acronym FICA stands for faith and belief, importance, community, and address in care. Questions around these topics can help assist a healthcare professional when assessing a patient's spiritual needs. Similarly, SPIRIT (Spiritual belief system, Personal spirituality, Integration in spiritual community, Ritualized practices, Implications for medical care, and Terminal events planning) and HOPE (sources of Hope, Organized religion, Personal spirituality and practice, and Effects on medical care and end-of-life issues) can be used by healthcare professionals for decision-making surrounding referrals to healthcare chaplains. Healthcare professionals benefit from spiritual assessment training in order to be more aware of the transdisciplinary care that can be offered to patients (Piotrowski, 2013).

1.1.8 Genetic Counseling and Spiritual Assessments

Spiritual assessments are performed and used by many genetic counselors (Reis et al., 2007). Reis et al. (2007) reported that approximately 60% of genetic counselors performed a spiritual assessment with a patient in the year 2007. However, only about 8.7% of genetic counselors performed a spiritual assessment in more than half of their sessions with patients. Genetic counselors felt more comfortable performing a spiritual assessment when the patient brought up the topic. Similar to the barriers healthcare professionals feel towards spiritual care of their patients, genetic counselors “may be
uncomfortable opening a discussion of spiritual factors out of concern that they will not be able to adequately address any spiritual turmoil that may be revealed,” feel as if they have a lack of training and “insufficient skills in spiritual assessment,” and have a lack of time with patients to discuss all of their spiritual needs (Reis et al., 2007).

1.1.9 Rationale

There is limited research assessing the overlap between healthcare chaplains and genetic counselors. To our knowledge, no research has been conducted studying the utilization of healthcare chaplains by genetic counselors. A previous study reported that some genetic counselors work closely with healthcare chaplains, including instances such as a congenital anomaly on a newborn or a miscarriage (Bartlett & Johnson, 2009). However, to our knowledge, there is no data that shows how frequently healthcare chaplains and genetic counselors work together. Another study found that genetic counseling patients with a high level of spiritual struggle are more likely to be open to religious actions and could benefit from a healthcare chaplain. Similarly, this study discovered that genetic counselors could assist patients that rely on religious coping methods by referring them to chaplaincy services (Sagaser et al., 2016).

Healthcare chaplains are the focus of this study because they may be a valuable resource within the existing healthcare system to genetic counselors when thinking about referrals for their patients.

1.1.10 Purpose of Study

This study was conducted in order to assess the current overlap between genetic counselors and healthcare chaplains. The aims of the study were:

1. Assess the utilization of healthcare chaplains by genetic counselors;
2. Determine the ability of healthcare chaplains to accept referrals from genetic counselors; and

3. Identify if patients would accept a referral to meet with a healthcare chaplain.

This study used an original electronic questionnaire with both quantitative and qualitative items to explore a number of topics regarding healthcare chaplains and their exposure to genetics and genetic counseling. An ancillary, original, electronic and paper/printed questionnaire exploring religion, spirituality, and guidance preference was distributed to prenatal, pediatric, and cancer genetic counseling patients at Prisma Health – Midlands and The Greenwood Genetic Center, Greenwood campus. We hypothesized that patients would consider talking with a healthcare chaplain. We hypothesized that healthcare chaplains are not currently being utilized by genetic counselors as resources for spiritual and nonspiritual patients. We hypothesized that healthcare chaplains have the ability, in time and skill, to accept referrals from genetic counselors.
CHAPTER 2

THE UTILIZATION OF HEALTHCARE CHAPLAINS BY GENETIC COUNSELORS

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2.1 Abstract

Healthcare chaplains prioritize the spiritual and religious care a patient and their family may need during their healthcare experience. This study investigated the current utilization of healthcare chaplains by genetic counselors, as well as the ability, in time and skill, of the healthcare chaplains to see genetic counseling patients. Lastly, the study investigated if genetic counseling patients would accept a referral to meet with a healthcare chaplain. We hypothesized that genetic counselors are not utilizing healthcare chaplains, healthcare chaplains have the ability, in time and skill, to see genetic counseling patients, and genetic counseling patients would consider meeting with a healthcare chaplain.

This study distributed an original electronic questionnaire to healthcare chaplains. An ancillary, original, electronic and paper/printed questionnaire was distributed to prenatal, pediatric, and cancer genetic counseling patients at Prisma Health – Midlands and The Greenwood Genetic Center, Greenwood campus. A mixture of percentages and frequencies were calculated as well as themes through a content analysis approach.

Data was collected from 253 healthcare chaplains (57.1% female; 41.6% male) and 110 genetic counseling patients (37.3% cancer; 9.1% general; 12.7% pediatric; 40.9% prenatal). Only 15.45% of healthcare chaplains claimed that a genetic counselor had referred a patient to them. More than 60% of healthcare chaplains felt comfortable, very comfortable, or extremely comfortable while discussing genetic syndromes or cancer susceptibility genes with patients and over 70% felt comfortable, very comfortable, or extremely comfortable with basic genetic concepts and medical
terminology. Lastly, around 45% of genetic counseling patients stated they would consider meeting with a healthcare chaplain.

Healthcare chaplains feel comfortable in their knowledge and skill to meet with genetic counseling patients but are not currently being widely used by genetic counselors as a referral. Genetic counselors should consider referring select patients who may be experiencing spiritual distress to healthcare chaplains.

2.2 Introduction

As defined by Roze des Ordones et al. (2020), “spirituality is a dynamic and intrinsic way in which we seek meaning, purpose, and transcendence” and “spiritual distress is the overwhelming sense of unrelieved suffering that happens when a person’s sense of meaning, purpose, connection, hope, or identity becomes acutely more vulnerable or is challenged”. Physical manifestations, such as disease progression, failed treatments, and symptoms such as pain and fatigue, have been associated with spiritual distress (Roze des Ordons et al., 2018). Similarly, spiritual well-being has been found to be negatively correlated with depression and anxiety (Kandasamy et al., 2011). For these reasons, managing spiritual distress in a healthcare setting may be beneficial to patients and their providers. Managing spiritual distress can be achieved through different approaches for different patients. For example, many African Americans turn to the Bible and prayer during times of illness and stressful life events (Hamilton et al., 2013, 2020). Similarly, many ICU patients want their spiritual needs to be assessed and fathers of ill-infants want to discuss spirituality to help with their lack of control in the situation (Gordon et al., 2018). Individuals that are not experiencing spiritual distress may also benefit from spiritual support in a healthcare setting. Spiritual support, or spiritual care,
may consist of religious practices, such as prayer, spiritual conversations around meaning, purpose, and hope, reflection, different counseling interventions, emotional support through empathy, or advocacy for the patient and their family (Roze des Ordones et al., 2020).

Many healthcare providers run into the challenge of how to deliver spiritual care to their patients (Peteet & Balboni, 2013). Barriers to providing spiritual care to patients include lack of time, inadequate training, lack of privacy, and the thought that spiritual care would be better offered by others (Balboni et al., 2014). Similar to the barriers healthcare professionals feel towards spiritual care of their patients, genetic counselors “may be uncomfortable opening a discussion of spiritual factors out of concern that they will not be able to adequately address any spiritual turmoil that may be revealed,” feel as if they have a lack of training and “insufficient skills in spiritual assessment,” and have a lack of time with patients to discuss all of their spiritual needs (Reis et al., 2007).

Along with the services genetic counselors provide to patients, spiritual care may be needed for many genetic counseling patients. For example, a literature review by Wiener et al. (2013) found that faith is important to parents of children receiving pediatric palliative care. Faith can “provide guidance, make sense of their situation, grant permission around end-of-life decision making, and to better cope” (Wiener et al., 2013). Similarly, cancer patients have indicated a desire for help with their spiritual needs and have shown that spiritual care can correlate with “better satisfaction with care, QOL (quality of life), psychological and spiritual adjustment, and less aggressive care at the end of life (EOL), as well as with attendant lower EOL costs, particularly among racial/ethnic minorities and high religious coping patients” (Peteet & Balboni, 2013).
Healthcare chaplains are trained to serve all faith groups, provide care through listening, serve on a patient care team, and provide guidance in the healthcare system (Association of Professional Chaplains et al., 2001). Educators of chaplains emphasize teaching the importance of working in a multifaith environment, using theological skills and knowledge to address suffering, and the identity and authority of the chaplain to their patients (Cadge et al., 2020). During times of illness and stress, people turn to spiritual resources for guidance and help. Chaplains play a role in “identifying patients in spiritual distress and helping them resolve their religious or spiritual problems, thus improving their health and adjustment” (Association of Professional Chaplains et al., 2001).

There is limited research assessing the overlap between healthcare chaplains and genetic counselors. To our knowledge, no research has been conducted studying the utilization of healthcare chaplains by genetic counselors and the potential benefits of referring spiritual or nonspiritual patients to healthcare chaplains. A previous study reported that some genetic counselors work closely with healthcare chaplains, including instances such as a congenital anomaly on a newborn or a miscarriage (Bartlett & Johnson, 2009). However, to our knowledge, there is no data that shows how frequently healthcare chaplains and genetic counselors work together. Another study found that genetic counseling patients with a high level of spiritual struggle are more likely to be open to religious actions and could benefit from a healthcare chaplain. Similarly, this study discovered that genetic counselors could assist patients that rely on religious coping methods by referring them to chaplaincy services (Sagaser et al., 2016).

Healthcare chaplains were the focus of this study because they may be a useful resource within the existing healthcare system to genetic counselors when thinking about
referrals for their patients. This study aimed to assess the utilization of healthcare chaplains by genetic counselors, determine the ability of healthcare chaplains to accept referrals from genetic counselors, and identify if patients would accept a referral to meet with a healthcare chaplain. It was hypothesized that healthcare chaplains were not being utilized by genetic counselors as resources for patients, healthcare chaplains have the ability, in time and skill, to accept referrals from genetic counselors, and patients would consider talking with a healthcare chaplain.

2.3 Materials and Methods

2.3.1 Participants

Participants included in this study were board certified healthcare chaplains or healthcare chaplains that have completed four units of clinical pastoral education (CPE). An ancillary survey included participants that had received genetic counseling from a genetic counselor at Prisma Health – Midlands or The Greenwood Genetic Center, Greenwood campus.

2.3.2 Research Methods

An invitational letter and infographic to take part in our survey was sent to board certified chaplains via Facebook groups and several email lists. The selection process for participation was based on individuals who identified as healthcare chaplains that lived and worked in the United States. The Facebook post was posted in the Facebook groups APC Professional Chaplain Discussion Page and Chaplaincy Innovation Lab - Chaplains’ Group and the email was sent through the HealthCare Chaplaincy Network (HCCN), the Association of Professional Chaplains (APC), the National Association of Catholic
Chaplains, healthcare chaplains through the South Carolina Chaplains Association, and pediatric chaplains through a national listserv.

Additionally, an invitation to participate in a survey was given to prenatal, cancer, and pediatric patients by their genetic counselor after a session. The selective process for participation was based on any individual who received genetic counseling from Prisma Health – Midlands or The Greenwood Genetic Center, Greenwood campus. The survey was printed for the participants to complete at the end of their visit or distributed electronically for virtual patients. A translated copy of the survey was provided by Hispanic Connections for Spanish speaking patients.

Participants were invited to take our online or printed survey and doing so served as their consent to participate. The survey given to board certified healthcare chaplains assessed the capacity of healthcare chaplains to see patients referred by genetic counselors. The survey given to genetic counseling patients assessed if patients would desire referrals to healthcare chaplains. We expected to determine if healthcare chaplains were exposed to genetics patients and their possible role as a referral base for patients. We also aimed to determine if patients would desire referrals to healthcare chaplains if suggested by a genetic counselor. The surveys consisted of questions including demographic information, Likert scale questions, multiple choice questions, and open-ended questions. The participants remained completely anonymous; no identifying information was collected on the survey.

2.3.3 Statistical Analysis and Statistical Methods

To address our research goals, we used descriptive statistical analysis using Microsoft Office Excel software. The majority of survey items resulted in categorical
information and therefore percentages and frequencies were calculated. For responses collected from open-ended questions, we used a content analysis approach to analyze and identify themes.

A total of 328 individuals responded to the healthcare chaplain survey. Of those, 11 responses were not included for analysis because the respondent was not board certified. Additionally, two responses were not included because the chaplains did not work in healthcare and two other responses were not included because the healthcare chaplain did not live and work in the United States. Lastly, 75 responses were not included for analysis due to incompletion. In total, 238 complete responses were used for data analysis. A total of 110 individuals responded to the genetic counseling patient survey, and in total, 110 complete responses were used for data analysis. Demographic information pertaining to the sample populations can be found in Table 2.1 and Table 2.2.

2.4 Results

2.4.1 Demographic Information

The Association of Professional Chaplains (APC) estimated they have 4,000 active members with about 3,000 members working in healthcare. Around 2,700 members of the APC are board certified. It is estimated that about 50% of APC members are male and 47.4% are female. Around 70% of APC members identify as white and 12% identify as Black or African American (White et al., 2021). Our demographic data showed a larger than expected number of female respondents than male respondents. Similarly, we had a larger than expected number of individuals who identify as White respond and a smaller than expected number of individuals who identify as Black or African American respond. Although our survey was sent out through other national
organizations, the APC had the largest response rate; therefore, we compared our demographic information to their organization’s demographic information.

2.4.2 **Objective 1: What is the utilization of healthcare chaplains by genetic counselors?**

To assess the utilization of healthcare chaplains by genetic counselors, we asked healthcare chaplains their familiarity with genetic counseling and their experience working with genetic counselors. Less than half of healthcare chaplains surveyed reported to be extremely familiar (10.82%; n=25) or moderately familiar (34.2%; n=79) with the profession of genetic counseling. More than half reported being only slightly familiar (37.23%; n=86) or not at all familiar (17.75%; n=41) with the profession of genetic counseling.

Only 15.45% of healthcare chaplains claimed that a genetic counselor had referred a patient to them. The majority claimed that a genetic counselor had never referred a patient to them (78.54%; n=183) and a small percentage was unsure (6.01%; n=14). To determine if the lack of referral was due to healthcare chaplains not seeing similar patients, we asked chaplains if they had ever consulted with a patient who had received genetic counseling. Almost half of the healthcare chaplains surveyed claimed that they had consulted with a patient who had received genetic counseling (46.78%; n=109). Conversely, 24.46% of chaplains claimed to have not consulted with patients who had genetic counseling (n=57) and 28.76% of healthcare chaplains were unsure (n=67). Over half of the healthcare chaplains reported that they frequently (19.82%; n=45) or occasionally (39.21%; n=89) consulted with a patient who had a higher susceptibility to cancer, while 23.79% and 17.18% of healthcare chaplains reported that
they rarely (n=54) or never (n=39) consulted with a patient who had a higher susceptibility to cancer, respectively.

2.4.3 Objective 2: What is the ability of healthcare chaplains to accept referrals from genetic counselors?

One portion of the survey asked questions in regard to healthcare chaplains’ ability, in the logistics of referrals and in their comfortability with the subject of genetics, to accept referrals from genetic counselors. The majority of healthcare chaplains frequently accepted referrals from healthcare providers within their healthcare system (80.26%; n=187). Otherwise, 15.02% of healthcare chaplains occasionally accepted referrals from healthcare providers within their healthcare system (n=35), 3% rarely accept referrals from healthcare providers within their healthcare system (n=7), and 1.72% never accept referrals from healthcare providers within their own healthcare system (n=4). Because genetic counselors can practice in a number of healthcare settings, healthcare chaplains were asked how frequently they accepted referrals from outpatient offices within their healthcare system. Only a portion of healthcare chaplains claimed to frequently accept referrals from outpatient offices within their healthcare system (15.22%; n=35). The majority of the healthcare chaplains claimed to rarely accept referrals from outpatient offices within their healthcare system (36.96%; n=85). The remainder of healthcare chaplains claimed to occasionally accept referrals from outpatient offices within their healthcare system (29.57%; n=68) and to never accept referrals from outpatient offices within their healthcare system (18.26%; n=42). Of those patients seen from an outpatient office referral, healthcare chaplains claimed to visit the patients one-on-one at bedside, by telephone or zoom, or in an office or private space.
To address comfort level with assisting medical decision-making and topics in genetics, respondents were asked to indicate their level of comfort with a number of relevant topics. These were broken into the categories: (1) medical terminology, (2) difficult conversations regarding medical decisions, (3) basic genetic concepts, (4) genetic syndromes, and (5) cancer susceptibility genes. Respondents could answer these questions with the following options: extremely uncomfortable, very uncomfortable, uncomfortable, comfortable, very comfortable, and extremely comfortable. Results can be seen in Figure 2.1.

Almost all healthcare chaplains felt comfortable, very comfortable, or extremely comfortable having difficult conversations regarding medical decisions with patients (95.68%; n=222). Overall, healthcare chaplains tended to feel less comfortable with genetic syndromes and cancer susceptibility genes with 63.95% and 63.52% of healthcare chaplains feeling comfortable, very comfortable, or extremely comfortable, respectively (n=149; n=148). Interestingly, 87.55% of healthcare chaplains felt comfortable, very comfortable, or extremely comfortable with medical terminology (n=204) and 70.82% of healthcare chaplains felt comfortable, very comfortable, or extremely comfortable with basic genetic concepts (n=171).

When asked where healthcare chaplains learned their knowledge of the subject of genetics, the majority answered on the job (39.66%; n=92). Few healthcare chaplains learned from board training (1.3%; n=3), continuing education (6.47%; n=15), personal research (5.17%; n=12), and school (9.05%; n=21). A number of healthcare chaplains reported they learned their knowledge of genetics from all of the avenues listed above, a combination of the above, work experience from another field, personal experience, or
learned from family or a colleague (21.98%; n=51). Only 16.38% of healthcare chaplains claimed not to feel comfortable with the subject of genetics.

When asked if they thought healthcare chaplains could be a beneficial resource to patients (and/or their families) receiving genetic counseling, 45.69% answered extremely (n=106), 46.55% answered very (n=108), and 7.33% answered slightly (n=17). Most notably, only one healthcare chaplain claimed that they did not think healthcare chaplains could be a beneficial resource to patients (and/or their families) receiving genetic counseling (0.43%).

To assess how healthcare chaplains may see themselves involved in the care of genetic counseling patients, four vignettes, describing four different genetic counseling scenarios, were presented on the survey (Table 2.3). Healthcare chaplains were asked what spiritual needs they saw in the scenario, as well as if they felt comfortable accepting a referral from a genetic counselor for that particular scenario. Three themes were found throughout all four vignettes: (1) Psychospiritual and existential distress, (2) Support for the individual and family, and (3) Assisting in processing thoughts and feelings (Table 2.4). Examples of each of these themes can be found in Table 2.5.

After reading vignette one, 155 healthcare chaplains stated they would feel comfortable receiving a referral from a genetic counselor (96.88%), three stated they would not feel comfortable receiving a referral from a genetic counselor (1.88%), and two stated maybe (1.25%). For vignettes two, three, and four, 145, 136, and 133 healthcare chaplains stated they would feel comfortable receiving a referral from a genetic counselor (92.95%, 91.89%, 95.0%), six, four, and three stated they would not
feel comfortable receiving a referral from a genetic counselor (3.85%, 2.70%, 2.14%), and five, eight, and four stated maybe (3.21%, 5.41%, 2.86%), respectively.

2.4.4 Objective 3: Would genetic counseling patients accept a referral to a healthcare chaplain?

Genetic counseling patients of different specialties were given the definition of a healthcare chaplain and asked whether or not they would consider talking with one regarding their current situation. When asked if the patient would consider talking to their spiritual leader/pastor/rabbi about their own or their child’s medical concerns, 48.18% said yes (n=53), 38.18% said no (n=42), and 13.64% preferred not to answer (n=15). When asked if the patient would consider talking to a healthcare chaplain about their own or their child’s medical concerns, 44.55% said yes (n=49), 42.73% said no (n=47), and 12.73% preferred not to answer (n=14). Finally, when asked if the patient would prefer talking to one over the other regarding their own or their child’s medical concerns, 40.91% said neither (n=45), 28.18% said both (n=31), 20% said their personal spiritual leader/pastor/rabbi (n=22), and 10.91% said a healthcare chaplain (n=12).

2.5 Discussion

Genetic counselors are trained to help individuals understand and process the implications of genetic contributions to disease. As with many other health professionals, genetic counselors are expected to practice within their scope (National Society of Genetic Counseling Code of Ethics, 2017). There have been many discussions regarding a genetic counselor's ability to assess and respond to patients’ spiritual or religious concerns (Scully et al., 2017; Thompson et al., 2016). Few studies, though, have mentioned the use of healthcare chaplains by genetic counselors in order to meet the
patients’ spiritual or religious concerns (Bartlett & Johnson, 2009; Sagaser et al., 2016). The results of this research provide a glimpse into the current utilization of healthcare chaplains by genetic counselors as a resource to certain patients, as well as the ability, in time and comfortability with genetics, for healthcare chaplains to accept referrals from genetic counselors.

We predicted that healthcare chaplains are not currently being regularly utilized by genetic counselors as a resource for spiritual and nonspiritual patients. However, we expected that healthcare chaplains would have the ability, in time and skill, to accept referrals from genetic counselors. Additionally, we predicted that genetic counseling patients would consider talking with a healthcare chaplain.

2.5.1 Objective 1: What is the utilization of healthcare chaplains by genetic counselors?

A minority of healthcare chaplains had received a referral from a genetic counselor or was familiar with the profession of genetic counseling. This result may suggest that not many genetic counselors are routinely referring patients to meet with healthcare chaplains. Conversely, about half of the healthcare chaplains reported that they had consulted with a patient who had received genetic counseling or has a higher susceptibility to cancer. This implies that there is an overlap between the patients being seen by genetic counselors and healthcare chaplains, but only a small number of genetic counseling patients are meeting healthcare chaplains through a referral from a genetic counselor. Of the healthcare chaplains that have received a referral from a genetic counselor, one stated that they meet patients “often at the genetic counselor’s office, sometimes at my office, and sometimes at a mutually agreed on outside location.”
Another chaplain mentioned “I work in outpatient oncology, so we have a team of genetic counselors.”

The means by which the other genetic counseling patients met with a healthcare chaplain is unknown (including who referred the patient to the chaplain or under what circumstances the patient saw the chaplain), or how long it took. Currently, there are no studies that have assessed the frequency genetic counselors refer their patients to healthcare chaplains.

2.5.2 Objective 2: What is the ability of healthcare chaplains to accept referrals from genetic counselors?

Healthcare chaplains typically consult with individuals through rounds, referrals from healthcare providers, and emergency on-call situations (Poncin et al., 2020). The majority of healthcare chaplains surveyed frequently accepted referrals from healthcare providers within their healthcare system. Less frequently, the healthcare chaplains reported to accept referrals from outpatient offices within their healthcare system. This information illustrates that if a healthcare chaplain is within the same healthcare system as a genetic counselor, a referral is logistically attainable. This suggests that genetic counselors, working inpatient or outpatient, have the ability to make such a referral. Bartlett & Johnson (2009) described an instance in which a genetic counselor calls the chaplain to meet with a family when a miscarriage or ultrasound anomaly occurs. This has the potential to be a standard referral that outpatient genetic counselors could make when an ultrasound anomaly is found, especially if a healthcare chaplain could meet the patient and family where the ultrasound is taking place.
Conversely, when discussing comfort level with receiving the referral from vignette one, one healthcare chaplain stated:

In all likelihood, I would meet the family regardless. As the pediatric chaplain, I would either interface with them through our palliative care service or in the NICU. It’s more likely I would meet them from those two sources than the genetic counselor.

This statement contradicts the notion that healthcare chaplains need a referral from genetic counselors to see certain genetic counseling patients, such as in the inpatient setting. Inpatient genetic counselors and healthcare chaplains may not need to interact as frequently because they are already seeing the same patients through rounds or an on-call basis. However, due to the overlap in patients they may be seeing, inpatient genetic counselors may be working more closely with healthcare chaplains due to proximity and accessibility.

More so than most clergy members or spiritual leaders, healthcare chaplains are trained and have clinical experience in the healthcare setting. Generally, healthcare patients have previously expressed a perceived lack of knowledge about genetics from members of their faith organization (Scully et al., 2017). For this reason, we assessed the comfortability of healthcare chaplains with medical terminology, difficult conversations regarding decision making, genetic syndromes, basic genetic concepts, and cancer susceptibility genes. More than 60% of healthcare chaplains felt comfortable, very comfortable, or extremely comfortable while discussing genetic syndromes or cancer susceptibility genes with patients and over 70% felt comfortable, very comfortable, or extremely comfortable with basic genetic concepts and medical terminology. This data
confirms that the majority of healthcare chaplains have a knowledge base in genetics, in addition to their training in psychosocial assessment and trauma, to be a potential resource to genetic counseling patients. Furthermore, because individuals’ spiritual leaders or clergy may not be as well versed in what the patient may be experiencing, a healthcare chaplain may be better suited to guide and talk with a genetic counseling patient.

Similarly, almost all of the healthcare chaplains surveyed reported that they felt comfortable, very comfortable, or extremely comfortable having difficult conversations regarding medical decisions with patients. This result not only shows that healthcare chaplains are familiar with facilitating decision-making, but also highlights their value as a potential resource to genetic counselors that may need guidance while helping a family, spiritual/non-spiritual or religious/non-religious, come to a difficult decision. Lemons et al. (2013) mentioned this idea by stating that genetic counselors could engage with healthcare chaplains in order to learn how to best incorporate religious and spiritual assessments in their sessions. Such a relationship would benefit genetic counselors that may feel as if they have a lack of training or insufficient skills in spiritual assessments (Reis et al., 2007).

All but one healthcare chaplain reported that they thought healthcare chaplains would be an extremely, very, or slightly beneficial resource to patients receiving genetic counseling. This further suggests the ability of healthcare chaplains to provide care to genetic counseling patients and emphasizes the current gap of care for genetic counseling patients. Four vignettes were provided to further assess how healthcare chaplains may be
involved in the care of genetic counseling patients. When asked what spiritual needs the healthcare chaplains saw in the scenario, three themes emerged.

The first theme healthcare chaplains identified in all four genetic counseling scenarios was psychospiritual and existential distress. All statements that included meaning-making, an individual’s sense of God or theodicy, spiritual distress, and value of life were included. Examples of statements given by the healthcare chaplains of this theme include, “why would God allow this,” “questioning why this happened,” “where is their own faith in this,” and “depending on their faith tradition what role does their belief system play.” Genetic counselors regularly talk with patients regarding how genetic contributions to disease occur, but the spiritual need of patients identified by the healthcare chaplains was struggling with questions of why they occur. Conversations regarding a patient’s sense of God or theodicy or why they think genetic contributions to disease occur may be additionally addressed by a healthcare chaplain following a referral from a genetic counselor.

The second theme found throughout all four vignettes was support for the individual and family. All statements that included coping strategies, facilitating decision-making, family dynamics, funeral/memorial planning, emotional, spiritual and physical support, etc. were included in this theme. One answer from a healthcare chaplain’s response to the second vignette that mentions family dynamics and facilitating decision-making is:

Fifteen is a time of emerging from the family as a differentiated adult, many times a difficult process and here more so. Allowing this young man to talk about his situation and what it means to have a limited life span and how he wants to deal
with those years is spiritual work. Letting a child make choices is challenging for parents: how closely do they hover and what tolerance do they have for what they don’t approve of is spiritual work. There are likely to be other family members who have a stake: siblings, grandparents (mothers-in-law, fathers-in-law), other family members who feel guilty or vulnerable (“could my child have this too?”)

All this and more can be addressed by a skilled chaplain.

Many genetic counseling sessions involve complex family dynamics and require tremendous support for the individuals and families. A referral to a healthcare chaplain in these scenarios may be beneficial not only to the genetic counselor, for sake of their time and ability to have these conversations with the family, but perhaps, more importantly, to the patients and their families.

The last theme addressing the spiritual needs in the vignettes was assisting in processing thoughts and feelings. Of all themes mentioned, assisting in processing thoughts and feelings was found in 70% of the answers in vignettes three and four, and 45% and 40% of the answers in vignettes one and two, respectively. All statements that included grief and loss, beliefs about death, suffering, anger, guilt, fear, uncertainty, hope, peace, and more were included in this theme. One healthcare chaplain described what a patient may be feeling in vignette one by stating they “might feel guilt and shame for being the passer-on of a defective gene.” Another healthcare chaplain answered the third vignette with:

Grief, loss, uncertainty, guilt. This scenario is different. The man has not, himself, received genetic counseling. In dealing with the enormous uncertainties and feelings in this situation, I’d certainly encourage the man to have his own testing
done. Sometimes the most “spiritual” advice one can give is the most practical—what might you do to set your mind at ease?

Genetic counselors and healthcare chaplains have clinical training in psychosocial assessment and support, but healthcare chaplains may be able to provide spiritual care that genetic counselors are not trained in. As Poncin et al. (2020) explains, chaplains use spiritual care to understand a person’s identity and meaning of life through talking and listening to them.

Over 90% of the healthcare chaplains stated that they would feel comfortable receiving a referral from a genetic counselor in the vignette scenarios. Some of the chaplains that were not comfortable receiving a referral used reasoning such as gender differences, age differences, lack of knowledge of that particular condition, or their own personal comfort. Some that answered they may or may not be comfortable accepting a referral from a genetic counselor said they would be more of a listening presence for the patient. This data strengthens the argument that healthcare chaplains have the ability to receive and accept referrals from genetic counselors to be a resource to genetic counseling patients.

2.5.3 Objective 3: Would genetic counseling patients uptake a referral to a healthcare chaplain?

Lastly, we surveyed genetic counseling patients from different clinical specialties to assess if they would consider meeting with a healthcare chaplain if referred by a genetic counselor. Around 45% of genetic counseling patients stated they would consider talking to a healthcare chaplain. When asked if the patient would prefer talking to a healthcare chaplain over their own spiritual or religious mentor, around 40% preferred a
healthcare chaplain or both a chaplain and their mentor. This was slightly less than the 80% of the genetic counseling patients who identified as being religious, spiritual, or both religious and spiritual. This data suggests that even though genetic counseling patients are religious or spiritual, they may not always want to meet with a healthcare chaplain or their own religious or spiritual mentor. However, this data also shows that a large number of genetic counseling patients would consider meeting with a healthcare chaplain following a genetic counseling appointment. It is worth noting that the majority of healthcare chaplains reported that they work with individuals of all faith groups, including individuals with no faith group. This is critical when assessing whether or not to refer a genetic counseling patient that may not consider themselves to be religious or spiritual to a healthcare chaplain.

2.5.4 Strengths and Limitations

A strength of this survey is that there are not any others of its kind. There have been some studies that mention the possibility of a working alliance between genetic counselors and healthcare chaplains, but none assessing the current overlap. In addition, this study was able to recruit a large, diverse sample that represents healthcare chaplains from across the United States.

A limitation of this study is the sample size of the genetic counseling patients (n=110). Similarly, the genetic counseling surveys were all distributed in South Carolina. This sample may not be generalizable to the whole United States due to the number of religious or spiritual individuals in the area and the effect it may have on their willingness to accept a referral to meet with a healthcare chaplain. We also did not assess the number
of responding chaplains that work in a setting where a genetic counselor is available. This may have skewed our data.

2.5.5 Practice Implications

Genetic counselors have the ability to utilize healthcare chaplains that work in their healthcare system. Whether or not a genetic counseling patient is religious/non-religious or spiritual/non-spiritual, they could benefit from seeing a healthcare chaplain if they need to further explore any spiritual distress they may be experiencing.

The results of this study support that it may be appropriate for genetic counselors to offer such a referral to their patients or explore the option of meeting with a chaplain if the patient desires. Furthermore, genetic counselors could commence building a relationship with their healthcare system’s chaplains in order to feel more comfortable utilizing them in the future.

2.5.6 Future Directions

This research is the first step in assessing and possibly developing the relationship between genetic counselors and healthcare chaplains. Because healthcare chaplains and genetic counseling patients were the focus of this research, genetic counselors would be the best next group to survey regarding this potential relationship. It would be interesting to know if genetic counselors report a similar number of referrals they give to healthcare chaplains, their past experiences working with healthcare chaplains, and their view of benefits and limitations of referring their patients to healthcare chaplains. Similarly, it would be interesting to survey genetic counseling patients, spiritual/non-spiritual or religious/non-religious, that have met with a healthcare chaplain related to a genetic
risk/diagnosis. This information may give us insight into the similarities and differences of support and resources genetic counselors and healthcare chaplains provide to patients.
Table 2.1 Healthcare Chaplain Demographic Information

<table>
<thead>
<tr>
<th>Variable</th>
<th>Descriptor</th>
<th>n  (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
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<td>133 (57.1)</td>
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<tr>
<td></td>
<td>Male</td>
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<tr>
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<tr>
<td></td>
<td>Yes, Mexican, Mexican American, Chicano</td>
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<tr>
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<td>Filipino</td>
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<tr>
<td></td>
<td>Other Pacific Islander</td>
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<td></td>
<td>Other race</td>
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<tr>
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<td>11 – 20</td>
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<td>Setting of practice</td>
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<td>Urban</td>
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<td>Religion/denominations service is provided to</td>
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<td></td>
<td>Buddhism</td>
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<td>Christianity</td>
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<td></td>
<td>Hinduism</td>
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<td></td>
<td>Islam</td>
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<td></td>
<td>Judaism</td>
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Other 3 (1.3)
Secular/Nonreligious/Agnostic/Atheist 0 (0)
### Table 2.2 Genetic Counseling Patient Demographic Information

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<th>Variable</th>
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<td><strong>Age</strong></td>
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<td>35 – 44</td>
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<td>Yes, Mexican, Mexican American, Chicano</td>
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<td>White, Vietnamese</td>
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<tr>
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<td>Abnormal prenatal screen</td>
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<td>Personal history of cancer</td>
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<td>Routine prenatal screen</td>
<td>16 (14.6)</td>
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Table 2.3 Genetic Counseling Vignettes

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<th>Vignette</th>
<th>Scenario</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A family has an amniocentesis that confirms a diagnosis of trisomy 18 in their child. The mother is 17 weeks along and has decided to continue the pregnancy. The family is struggling with accepting the prognosis of trisomy 18. The genetic counselor informed the family that most children born with this condition only live for a few days or weeks.</td>
</tr>
<tr>
<td>2</td>
<td>A boy is diagnosed with Duchenne Muscular Dystrophy at a young age. He is currently 15 years old and has lost his ability to walk. His parents are struggling with his prognosis, as they were told most boys with DMD pass away around age 25. The son is frustrated with his condition and the way his parents treat him.</td>
</tr>
<tr>
<td>3</td>
<td>A woman was recently diagnosed with Ovarian cancer. She sees a genetic counselor and is found to be a carrier of a mutation in the <em>BRIP1</em> gene. This mutation is known to increase a woman’s lifetime risk of ovarian cancer from 2-3% to around 10%. She feels guilty because there is a 50% chance that she passed this mutation on to her 3 daughters.</td>
</tr>
<tr>
<td>4</td>
<td>A man recently discovered his brother had a genetic syndrome called Long QT Syndrome. His brother passed away at age 40 due to a sudden heart attack. The man realizes that he is at risk to having the same condition as his brother. He is worried about his health and his children.</td>
</tr>
<tr>
<td>Vignette</td>
<td>Themes</td>
</tr>
<tr>
<td>----------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>1</td>
<td>Psychospiritual and existential distress</td>
</tr>
<tr>
<td></td>
<td>Support for individual and family</td>
</tr>
<tr>
<td></td>
<td>Assisting in processing thoughts and feelings</td>
</tr>
<tr>
<td>2</td>
<td>Psychospiritual and existential distress</td>
</tr>
<tr>
<td></td>
<td>Support for individual and family</td>
</tr>
<tr>
<td></td>
<td>Assisting in processing thoughts and feelings</td>
</tr>
<tr>
<td>3</td>
<td>Psychospiritual and existential distress</td>
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<tr>
<td></td>
<td>Support for individual and family</td>
</tr>
<tr>
<td></td>
<td>Assisting in processing thoughts and feelings</td>
</tr>
<tr>
<td>4</td>
<td>Psychospiritual and existential distress</td>
</tr>
<tr>
<td></td>
<td>Support for individual and family</td>
</tr>
<tr>
<td></td>
<td>Assisting in processing thoughts and feelings</td>
</tr>
</tbody>
</table>
Table 2.5 Examples of Spiritual Need Themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychospiritual and existential distress</td>
<td>Meaning-making&lt;br&gt;Sense of God/Theodicy&lt;br&gt;Value of life&lt;br&gt;Spiritual distress&lt;br&gt;Faith</td>
</tr>
<tr>
<td>Support for the individual and family</td>
<td>Exploring values and source of purpose for the family&lt;br&gt;Identifying emotional, spiritual, and physical support&lt;br&gt;Funeral/memorial planning&lt;br&gt;Family dynamics&lt;br&gt;Protection&lt;br&gt;Coping strategies&lt;br&gt;Compassionate presence/listening&lt;br&gt;Facilitating decision-making&lt;br&gt;Strength affirmations&lt;br&gt;Independence/autonomy</td>
</tr>
<tr>
<td>Assisting in processing thoughts and feelings</td>
<td>Grief/loss (past, present, anticipatory)&lt;br&gt;Abandonment&lt;br&gt;Beliefs about death/dying&lt;br&gt;Suffering&lt;br&gt;Anger&lt;br&gt;Guilt/blame&lt;br&gt;Fear&lt;br&gt;Uncertainty/doubt&lt;br&gt;Loss of power/control&lt;br&gt;Hope&lt;br&gt;Peace&lt;br&gt;Comfort&lt;br&gt;Acceptance/denial</td>
</tr>
</tbody>
</table>
Figure 2.1 Healthcare chaplains’ comfortability with cancer susceptibility genes, basic genetic concepts, medical terminology, genetic syndromes, and difficult conversations regarding medical decisions.
CHAPTER 3

CONCLUSION

Healthcare chaplains serve an important role for patients that may be experiencing spiritual distress. They are not only trained to serve people of different faith traditions, but have experience and familiarity with medical terminology, basic genetic concepts, and difficult conversations. Genetic counselors take into account many different aspects of a patients’ life in order to give them the best and appropriate care, including their faith and cultural beliefs. However, genetic counselors are required to work within their scope of practice, which may not always answer all patients’ existential or spiritual questions. In such instances, genetic counselors should consider placing referrals for certain patients to meet with a healthcare chaplain within their healthcare system.
REFERENCES


Association of Professional Chaplains, Association for Clinical Pastoral Education, Canadian Association for Pastoral Practice and Education, National Association of Catholic Chaplains, & National Association...


https://doi.org/10.1016/j.jcrc.2018.01.015


https://doi.org/10.1007/s10943-019-00809-7


Lemons, J., Ragsdale, J., Vaughn, L., & Grossoehme, D. (2013). "I didn't know it existed before you called": Protestant clergy experience, education and perceptions

https://doi.org/10.1007/s10897-012-9538-2


National Society of Genetic Counselors. *About Genetic Counselors*. https://www.nsgc.org/About/About-Genetic-Counselors


https://doi.org/10.2190/OM.67.1-2.v


APPENDIX A: STUDY RECRUITMENT EMAIL 1

Request for Participation:
Study on the Topic of Healthcare Chaplains

November 23, 2021

Dear APC membership,

Grace Hollingworth is a genetic counseling graduate student at the University of South Carolina School of Medicine. Grace is currently participating in research that assesses the involvement of healthcare chaplains in the medical care of genetics patients. Grace invites you to complete a brief survey that looks at the experience of the chaplain, your knowledge in genetics/medical terminology, your experience working (or not working) with genetic counselors, and your thoughts on whether or not you would be a good resource for genetic counselors to give to patients. Board certified chaplains (or chaplains that have completed 4 units of CPE) that live and work in the United States and have worked in healthcare are eligible to participate. The survey will close two weeks from this mailing. Thank you for considering and helping advance the knowledge we have about this topic. If you do participate and are interested in a summary of the results, please email Grace at Elizabeth.Hollingsworth@uscmed.sc.edu expressing your interest and providing your email address.

To complete the survey, please follow this link:
https://uofsc.co1.qualtrics.com/jfe/form/SV_9GNpNHqN5azFq0S.

If you complete the optional vignettes at the end of the survey, please follow this link to enter into a raffle to win a $25 gift card:
https://uofsc.co1.qualtrics.com/jfe/form/SV_yyO0Dh9OaStt7Bc.

Thank you for your consideration.

Stephen King PhD BCC
Chair, Joint Research Council
Dear Chaplains,

This IRB approved study through The University of South Carolina aims to assess healthcare chaplains involvement in medical care related to genetics.

We are asking healthcare chaplains to take a survey that will take anywhere from 20 to 40 minutes. All responses gathered from the survey will be kept anonymous and confidential. The results of this study might be published or presented at academic meetings; however, participants will not be identified.

There is also an option to volunteer to complete four additional questions at the end of this survey. Completion of these questions will allow you to enter a raffle for the chance to win one of three $25 Amazon gift cards. Please only enter into the raffle if you have completed the survey and the additional four questions.

Survey: https://uofsc.co1.qualtrics.com/jfe/form/SV_9GNpNHqN5azFq0S
Raffle: https://uofsc.co1.qualtrics.com/jfe/form/SV_9yOODh9Oastt7Be

Thank you for your contribution to this important research. We are looking forward to seeing how we can better assist our patients' spiritual and religious needs!

Best,

Grace Hollingsworth
Genetic Counseling Intern
University of South Carolina
School of Medicine
elizabeth.hollingsworth@uscmed.sc.edu
APPENDIX C: STUDY RECRUITMENT INFOGRAPHIC

RECRUITING BOARD CERTIFIED HEALTHCARE CHAPLAINS

Research through The University of South Carolina School of Medicine

Goal: Assess healthcare chaplains involvement in medical care related to genetics

Survey time: Approximately 10 - 20 minutes

IRB approved through Health Sciences South Carolina

To take the survey, you can scan the QR code above or go to:
https://uofsc.col.qualtrics.com/jfe/form/SV_9GNpNHqN5azFqDS
APPENDIX D: STUDY RECRUITMENT FACEBOOK POST

We are looking for US healthcare chaplains that are board certified or have completed four units of CPE to take our survey. This study is being conducted in order to assess the current overlap between genetic counselors and healthcare chaplains. We primarily aim to determine if healthcare chaplains are being underutilized by genetic counselors as a resource to religious and nonreligious patients. We also hope to assess the likelihood patients will uptake referrals from genetic counselors to healthcare chaplains.

All responses gathered from the survey will be kept anonymous and confidential. The results of this study might be published or presented at academic meetings; however, participants will not be identified.

There is also an option to volunteer to complete four additional questions at the end of this survey. Completion of these questions will allow you to enter a raffle for the chance to win one of three $25 Amazon gift cards.

Survey: https://uofsc.co1.qualtrics.com/jfe/form/SV_9GpNHqN5azFqO5S

Raffle: https://uofsc.co1.qualtrics.com/jfe/form/SV_9yOODh90astt7Bc
APPENDIX E: HEALTHCARE CHAPLAIN SURVEY

Thank you for considering to participate in the study of The Utilization of Healthcare Chaplains by Genetic Counselors. This questionnaire will contain a series of multiple choice, multi-select, slider scale, and open-ended questions attempting to understand if the utilization of board certified healthcare chaplains is helpful to genetic counselors. Your participation is completely voluntary and you may choose to skip questions if you prefer not to answer. All responses gathered from the survey will be kept anonymous and confidential. The results of this study might be published or presented at academic meetings; however, participants will not be identified. The last page of this survey will contain a separate link where you may enter a raffle for the chance to win one of three $25 Amazon gift cards by volunteering to complete three additional questions at the end of this survey. If you are willing to participate in this study, please click the "next" button below. If not, please exit the browser.

End of Block: Introduction

Start of Block: Inclusion Criteria

Q1 Are you a board certified chaplain or have completed four units of CPE?

○ Yes (1)

○ No (2)

Skip To: End of Survey If Are you a board certified chaplain or have completed four units of CPE? = No
Q2 Please select all specialties you have worked in

☐ Healthcare (1)

☐ Other (2)

*Skip To: End of Survey If Please select all specialties you have worked in != Healthcare*

Q3 Do you live and work in the United States?

☐ Yes (1)

☐ No (2)

*Skip To: End of Survey If Do you live and work in the United States? = No*

End of Block: Inclusion Criteria

Start of Block: Accessibility and Client Population

Q11 How frequently do you accept referrals from healthcare providers within your healthcare system?

☐ Never (1)

☐ Rarely (2)

☐ Occasionally (3)

☐ Frequently (4)
Q12 How frequently do you accept referrals from outpatient offices within your healthcare system?

- Never (1)
- Rarely (2)
- Occasionally (3)
- Frequently (4)
Display This Question:

If How frequently do you accept referrals from outpatient offices within your healthcare system? != Never

Q13 How do you meet with the patient?

________________________________________________________________

Display This Question:

If How frequently do you accept referrals from outpatient offices within your healthcare system? = Never

Q14 Please explain why.

________________________________________________________________

Page Break
Q15 How do you determine which patients you see?

- Census (1)
- Referrals from physicians (2)
- Referrals from other members of the patient's care team (3)
- Other, please specify (4)

Q16 Have you ever consulted with a patient who has a genetic condition or a patient's family?

- Never (1)
- Rarely (2)
- Occasionally (3)
- Frequently (4)

Display This Question:

If Have you ever consulted with a patient who has a genetic condition or a patient's family? != Never

Q29 Please list which genetic conditions you consulted the patient or patient's family about.

________________________________________________________________________
Q30 Have you ever consulted with a patient who has a higher susceptibility to cancer?

- Never (1)
- Rarely (2)
- Occasionally (3)
- Frequently (4)

End of Block: Accessibility and Client Population

Start of Block: Genetics Education
Q17 Indicate your level of comfort with the following topics related to medical care and genetics.

<table>
<thead>
<tr>
<th>Medical terminology (1)</th>
<th>Extremely uncomfortable (1)</th>
<th>Very uncomfortable (2)</th>
<th>Uncomfortable (3)</th>
<th>Comfortable (4)</th>
<th>Very comfortable (5)</th>
<th>Extremely comfortable (6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficult conversations regarding medical decisions (2)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Basic genetic concepts (3)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Genetic syndromes (4)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Cancer susceptibility genes (5)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

Page Break
Q18 If you feel comfortable with the subject of genetics, where did you learn your knowledge of the subject?

- School (1)
- Board training (2)
- On the job (3)
- Continuing education (4)
- Personal research (5)
- Other, please specify (6)

I do not feel comfortable with the subject of genetics (7)

End of Block: Genetics Education

Start of Block: Familiarity with Genetic Counseling

Q19 Are you familiar with the profession of genetic counseling?

- Not at all familiar (1)
- Slightly familiar (2)
- Moderately familiar (3)
- Extremely familiar (4)
Q20 Has a genetic counselor referred a patient to you?

- Yes (1)
- No (2)
- Unsure (3)

Q21 Have you ever consulted with a patient who has received genetic counseling?

- Yes (1)
- No (2)
- Unsure (3)
Q0 The National Society of Genetic Counselors defines genetic counseling as the process of helping people understand and adapt to the medical, psychological, and familial implications of the genetic contributions to disease. This process integrates: (1) Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence. (2) Education about inheritance, testing, management, prevention, resources and research. (3) Counseling to promote informed choices and adaptation to the risk or condition.

Q22 Do you think healthcare chaplains could be a beneficial resource to patients (and/or their families) receiving genetic counseling?

☐ Not at all (1)
☐ Slightly (2)
☐ Very (3)
☐ Extremely (4)

Q26 Please explain why.

End of Block: Familiarity with Genetic Counseling

Start of Block: Demographics

Q4 What gender do you identify as?

☐ Male (1)
☐ Female (2)
☐ Other, please specify (3)
Q5 Are you of Hispanic, Latino, or Spanish origin?

- No, not of Hispanic, Latino, or Spanish origin (1)
- Yes, Mexican, Mexican American, Chicano (2)
- Yes, Puerto Rican (3)
- Yes, Cuban (4)
- Yes, another Hispanic, Latino, or Spanish origin (please specify) (5)
Q6 What is your race? (select one or more boxes)

- □ White (1)
- □ Black or African American (2)
- □ American Indian or Alaska Native (3)
- □ Chinese (4)
- □ Vietnamese (5)
- □ Native Hawaiian (6)
- □ Filipino (7)
- □ Korean (8)
- □ Samoan (9)
- □ Asian Indian (10)
- □ Japanese (11)
- □ Chamorro (12)
- □ Other Asian (please specify) (13)
- □ Other Pacific Islander (please specify) (14)
- □ Other race (please specify) (15)
Q7 What is the highest degree or level of education you have completed?

- Master's Degree (1)
- Doctoral Degree (2)
- Other, please specify (3)

Q8 How many years have you been serving as a healthcare chaplain?

- 0 - 10 (1)
- 11 - 20 (2)
- 21 - 30 (3)
- 31 - 40 (4)
- 41 - 50 (5)
- 50+ (6)

Q9 In what type of setting do you practice?

- Urban (1)
- Suburban (2)
- Rural (3)
Q10 What religions/denominations do you provide service to?

- Christianity (1)
- Islam (2)
- Hinduism (3)
- Buddhism (4)
- Judaism (5)
- Secular/Nonreligious/Agnostic/Atheist (6)
- Other, please specify (7)
- All of the above (8)
- None of the above (9)

End of Block: Demographics

Start of Block: Optional Vignettes

Q27 Would you like to answer four additional open-ended questions to be entered into a raffle to win a $25 amazon gift card?

- Yes (1)
- No (2)

Skip To: End of Survey If Would you like to answer four additional open-ended questions to be entered into a raffle to win... = No

Q28 The following four scenarios are examples of patients that a variety of genetic counselors would work with. Please read each scenario and answer the three questions that follow.
Q31 A family has an amniocentesis that confirms a diagnosis of trisomy 18 in their child. The mother is 17 weeks along and has decided to continue the pregnancy. The family is struggling with accepting the prognosis of trisomy 18. The genetic counselor informed the family that most children born with this condition only live for a few days or weeks.

Q35 What spiritual needs do you see in this situation?

________________________________________________________________

Q39 Would you be comfortable receiving a referral from a genetic counselor to see this patient? Why or why not?

________________________________________________________________

Q43 Please describe what you would say to this patient.

________________________________________________________________
Q32 A boy is diagnosed with Duchenne Muscular Dystrophy at a young age. He is currently 15 years old and has lost his ability to walk. His parents are struggling with his prognosis, as they were told most boys with DMD pass away around age 25. The son is frustrated with his condition and the way his parents treat him.

Q36 What spiritual needs do you see in this situation?

________________________________________________________________

Q40 Would you be comfortable receiving a referral from a genetic counselor to see this patient? Why or why not?

________________________________________________________________

Q44 Please describe what you would say to this patient.

________________________________________________________________
Q33 A woman was recently diagnosed with Ovarian cancer. She sees a genetic counselor and is found to be a carrier of a mutation in the BRIP1 gene. This mutation is known to increase a woman’s lifetime risk of ovarian cancer from 2-3% to around 10%. She feels guilty because there is a 50% chance that she passed this mutation on to her 3 daughters.

Q37 What spiritual needs do you see in this situation?

________________________________________________________________

Q41 Would you be comfortable receiving a referral from a genetic counselor to see this patient? Why or why not?

________________________________________________________________

Q45 Please describe what you would say to this patient.

________________________________________________________________

Page Break
Q34
A man recently discovered his brother had a genetic syndrome called Long QT Syndrome. His brother passed away at age 40 due to a sudden heart attack. The man realizes that he is at risk to having the same condition as his brother. He is worried about his health and his children.

Q38 What spiritual needs do you see in this situation?

________________________________________________________________

Q42 Would you be comfortable receiving a referral from a genetic counselor to see this patient? Why or why not?

________________________________________________________________

Q46 Please describe what you would say to this patient.

________________________________________________________________

End of Block: Optional Vignettes

Start of Block: Conclusion

Q27 Thank you for your time and consideration to participate in this survey. Your responses may help inform genetic counselors on the usefulness of the utilization of hospital chaplains in practice. If you have any questions regarding the research, you may contact either myself or my faculty advisor, Debera Zvejnieks, MS, CGC, using the contact information below. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803) 777-7095.
APPENDIX F: GENETIC COUNSELING PATIENT SURVEY IN ENGLISH

Thank you for considering to participate in the study of The Utilization of Healthcare Chaplains by Genetic Counselors. This survey will contain ten multiple choice questions attempting to identify if patients would utilize healthcare chaplains if offered to them. Your participation is completely voluntary and you may choose to skip questions if you prefer not to answer. All responses gathered from the survey will be kept anonymous and confidential. The results of this study might be published or presented at academic meetings; however, participants will not be identified.

End of Block: Information

Start of Block: Demographic

Q1 What age group do you fall into?

- 18 - 24 (1)
- 25 - 34 (2)
- 35 - 44 (3)
- 45 - 54 (4)
- 55+ (5)
Q2 Are you of Hispanic, Latino, or Spanish origin?

- No, not of Hispanic, Latino, or Spanish origin (1)
- Yes, Mexican, Mexican American, Chicano (2)
- Yes, Puerto Rican (3)
- Yes, Cuban (4)
- Yes, another Hispanic Latino, or Spanish origin (please specify) (5)

________________________________________________
Q3 What is your race?

- [ ] White (1)
- [ ] Black or African American (2)
- [ ] American Indian or Alaska Native (3)
- [ ] Chinese (4)
- [ ] Vietnamese (5)
- [ ] Native Hawaiian (6)
- [ ] Filipino (7)
- [ ] Korean (8)
- [ ] Samoan (9)
- [ ] Asian Indian (10)
- [ ] Japanese (11)
- [ ] Chamorro (12)
- [ ] Other Asian (please specify) (13)
- [ ] Other Pacific Islander (please specify) (14)
- [ ] Other race (please specify) (15)
Q4 What clinic are you being seen in?

- Cancer (1)
- Prenatal (2)
- Pediatric (3)
- General (4)

Q5 What is your reason for referral?

- Abnormal carrier screen (1)
- Abnormal prenatal screen (2)
- Advanced maternal age (3)
- Family history of cancer (4)
- Family history of a genetic condition (5)
- Follow-up management (6)
- Personal history of cancer (7)
- Personal history of a developmental disorder (8)
- Personal history of a genetic condition (9)
- Results disclosure (10)
- Routine prenatal screen (11)
- Other (please specify) (12)
Q6 A healthcare chaplain gives spiritual and emotional support to patients and their families as they deal with their medical needs. Chaplains work with people of any or no faith tradition/religion to care for whatever spiritual needs they have. Please select one answer to each multiple choice question.

Q7 Do you consider yourself to be:
   ○ Religious  (1)
   ○ Spiritual  (2)
   ○ Both  (3)
   ○ Neither  (4)

Q8 Would you consider talking to your spiritual leader/pastor/rabbi about your or your child's medical concerns?
   ○ Yes  (1)
   ○ No  (2)
   ○ Prefer not to answer  (3)

Q9 Would you consider talking to a hospital/healthcare chaplain about your or your child's medical concerns?
   ○ Yes  (1)
   ○ No  (2)
   ○ Prefer not to answer  (3)
Q10 Would you prefer talking to one over the other regarding your or your child's medical concerns?

- Your personal spiritual leader/pastor/rabbi (1)
- Hospital/healthcare chaplain (2)
- Both (3)
- Neither (4)

End of Block: Chaplain
Gracias por participar en el estudio de La Utilizacion de los Consultores de Atencion Médica por Consultores Genéticos. Ésta encuesta consta de diez preguntas de selección múltiple para identificar si los pacientes utilizarían los servicios de consultores genéticos si se les ofreciera el servicio. Su participación es voluntaria y pudiera no responder a una pregunta si así lo deseara. Todas las respuestas son totalmente anónimas y confidenciales. Los resultados de este estudio podrían ser publicados o presentados en reuniones académicas; sin embargo, no se daría a conocer la identidad del encuestado.

Cuál es su edad?

- 18 - 24 (1)
- 25 - 34 (2)
- 35 - 44 (3)
- 45 - 54 (4)
- 55+ (5)
Q2 ¿Usted es hispano, latino, o de origen hispano?

- No, no soy hispano, latino, o de origen (1)
- Sí, mejicano, mejicano americano, chicano (2)
- Sí, puertorriqueño (3)
- Sí, cubano (4)
- Sí, otro hispano latino, o de origen hispano (por favor especifique) (5)
Q3 Cuál es su raza?

- Blanco (1)
- Afro americano (2)
- Indio americano o nativo de Alaska (3)
- Chino (4)
- Vietnamita (5)
- Nativo de Hawaii (6)
- Filipino (7)
- Koreano (8)
- Samoano (9)
- Indo asiático (10)
- Japonés (11)
- Chamorro (12)
- Otro de Asia (por favor especifique) (13)
- Otro isla del Pacífico (por favor especifique) (14)
- Otra raza (por favor especifique) (15)
Q4 En qué servicio lo atienden?

- Cáncer (1)
- Prenatal (2)
- Pediátrico (3)
- General (4)

Q5 Motivo por el cuál lo remiten?

- Prueba de portador anormal (1)
- Prueba prenatal anormal (2)
- Edad maternal avanzada (3)
- Historia familiar de cáncer (4)
- Historia familiar de un defecto genético (5)
- Control, seguimiento (6)
- Historia personal de cáncer (7)
- Historia personal de un defecto del desarrollo (8)
- Historia personal de un defecto genético (9)
- Lectura de resultados (10)
- Prueba prenatal rutinaria (11)
- Otro (por favor especifique) (12)
Q7 Un consultor de salud da apoyo espiritual y emocional a los pacientes y a sus familiares a la medida de sus necesidades médicas. Los consultores trabajan con personas de cualquier religión o cultura brindando cuidado sin importar sus necesidades espirituales. Por favor seleccione una respuesta a cada una de las preguntas de selección multiple.

Q8 Usted se considera una persona:

- Religiosa (1)
- Espiritual (2)
- Ambas (3)
- Ninguna (4)

Q9 Le gustaría hablar con su líder espiritual/pastor/rabino acerca de sus necesidades médicas o las de su hijo?

- Si (1)
- No (2)
- Prefiere no responder (3)

Q10 Consideraría hablar con un consultor del hospital o de la salud acerca de sus necesidades médicas o las de su hijo?

- Si (1)
- No (2)
- Prefiere no contestar (3)
Q11 Con quién preferiría hablar acerca de sus necesidades médicas o las necesidades médicas de su hijo?

- Su líder espiritual personal/pastor/rabino (1)
- Consultor del hospital o de la salud (2)
- Ambos (3)
- Ninguno (4)

End of Block: Chaplain