

Testing Options, Interpretation, and Results: Spirituality and Religion in the Genetic Counseling Setting

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Learning Objectives*

By the end of this case, genetic counselors will be able to:

1. Explain the steps involved in discussing testing options, interpretation, and results.
2. Elicit and interpret individual and family experience, behaviors, emotions, perceptions and attitudes that may clarify clients' religious and spiritual beliefs and values.
3. Increase awareness of factors that contribute to decision making in genetic counseling settings.
4. Incorporate assessment and discussion of religion and spirituality in genetic counseling sessions.
5. Facilitate decision making in an unbiased, non-coercive manner.

*Learning objectives are modified from "Making Sense of Genetic Uncertainty: The Role of Religion and Spirituality" (White, 2009).

Case Study

Amanda recently began working as the only genetic counselor in a high risk prenatal care center. Today, Amanda is meeting with Ori and her husband Tal, who were referred for ultrasound findings of cleft lip, congenital brain malformation (no cerebellum), heart anomalies, and intrauterine growth retardation in the fetus (26 weeks gestation). Before the session, Amanda is told by the geneticist and cardiologist that the fetus probably has Trisomy 13 and is not expected to survive until birth. Amanda's role is to share this information with the couple, assess whether they would like to proceed with any testing, and develop a plan for next steps. Amanda plans to provide psychosocial support and to discuss amniocentesis with the couple.

When Amanda walks into the room to greet Ori and Tal, she finds the couple with their heads bowed down. After a minute of silence, Ori and Tal look up and explain to Amanda that they felt a prayer was needed before the genetic counseling session. Amanda feels nervous, but smiles warmly. Then, she launches into breaking the bad

news. When the couple hears that the baby is likely to have a chromosomal condition, Ori shakes her head and cries out, "That it is not possible!" Ori tells the genetic counselor that the baby is the reincarnation of her father who passed away only 5 months ago. At the end of his life, Ori's father had severe heart problems and Alzheimer's disease. Although she would not dare say this to anyone, Ori had feared that her baby would have the same problems as her father.

Amanda is not sure what to think, believe, or respond to this unexpected explanation. She debates in her head whether she should discuss amniocentesis with the couple. Amanda rationalizes that if she dwells on discussing testing options, she would not be respecting Ori and Tal's beliefs. She asks the couple if they would like to speak to the geneticist. Tal, who has been quiet, says that he and his wife don't want any testing and they don't want to see any more specialists. "We must not disturb the baby's spirit." Ori and Tal rise to leave. Amanda is speechless.

Personal Reflections

- What are your first reactions to this case?
- Have you ever experienced a situation like this? What were the similarities to this session? What were the differences?
- What are the potential personal and/or religious reasons for Amanda's feelings of uncertainty?
- Did this situation cause you to question your knowledge, skills, ability and/or willingness to effectively serve all patients?
- What assumptions have you made about Ori and Tal?
- What thoughts do you have about further exploring the context of this couple's religious and spiritual beliefs and practices?
- What are your personal views toward religion and spirituality?
- Write down any questions you typically ask about clients' religion and/or spirituality. Why do you ask these specific questions?
- What are your thoughts about the role of prayer in health care settings in general, and specifically in the genetic counseling setting?
- How did you feel when Ori said the baby was a reincarnation of her father? Why do you think you felt that way?
- Do you consider yourself to be religious or spiritual? If so, consider whether your religiosity/spirituality has changed over time and in specific situations.

- What is your personal experience with receiving “life-changing” news? What was the role of your own religious or spiritual views in receiving and coping with the news, and dealing with any associated decisions and consequences?

Perspectives

Now approach the situation from the clients’ point of view. Consider the religious or spiritual beliefs underlying Ori and Tal’s emotions and responses.

- Identify the thoughts and feelings Ori might have.
- Identify the thoughts and feelings Tal might have.
- List the signs of religious or spiritual views demonstrated by the couple.
- How might Amanda’s actions and reactions have influenced the couple?
- How might the clients’ previous interactions with health care providers have influenced their actions and reactions in this session?
- How might the client’s previous interactions with friends and family have influenced their actions and reactions in this session?

Religion and Spirituality

“If you live in the United States today, you live in a nation in which there are about as many Hindu practitioners as Orthodox Jews, more Buddhists than Seventh-Day Adventists, and more followers of Islam than Episcopalians” (Toropov & Buckles, 2004). America has often been coined the melting pot for a multitude of cultures and religions that all exist within one country. Previously, religious and cultural tolerance meant simply acknowledging differences within various traditions. Today, that definition is insufficient to encompass the increasing diversity in America. Gaining a broad understanding of various religions and cultures is imperative for helping health care providers respect each person as an individual and collaborate effectively (Toropov & Buckles, 2004).

Before exploring various religions and learning tools to assess religion and spirituality in a genetic counseling session, it is first important to define religion and spirituality. Religion is most commonly described “a set of principles usually related to a higher power and established in an institution” (Cadge et al., 2009). The root of this word comes from the Latin term *religare*, meaning “to bind together.” Religion generally provides an organized structure of beliefs and practices especially pertaining to relationships with God and others (Spirituality and Palliative Care, 2009). Each religion offers a unique framework for guiding affiliated individuals. In some religions, it is simply enough to believe in God, while other religions place greater emphasis on practice. Some religions focus more on the individual; others emphasize the community.

Regardless of the structure, the ultimate goal of religion is to provide followers with concrete ways of expressing their spirituality (Spirituality and Palliative Care, 2009).

In comparison, spirituality commonly describes “a wider range of ways people find meaning in their lives” (Cadge et al, 2009). The root of this word stems from the Latin term *spiritualitas* meaning “breath.” Spirituality is a “personalized system of beliefs through which one understands the meaning and purpose in life” (Spirituality and Palliative Care, 2009). Spirituality is not simply restricted to explaining one’s relationship with a higher being, but it can also broadly refer to “nature, energy, force, belief in the good of all, belief in the importance of family and community,” and other factors (Spirituality and Palliative Care, 2009).

There are numerous concepts, relationships, rituals and symbols that individuals consider to be “sacred.” What do you think of when you hear the word ‘sacred’? What do you personally consider to be ‘sacred’? Have you ever considered this topic within the framework of genetic counseling practice? The psychologist Kenneth I. Pargament and the advocate Winona LaDuke explore the sacred in great depth in their books, respectively: *Spiritually Integrated Psychotherapy: Understanding and Addressing the Sacred* (2007), and *Recovering the Sacred: The Power of Naming and Claiming* (2005). The authors discuss perspectives of people from Western cultural backgrounds and those from American Indian backgrounds, respectively, providing an interesting opportunity to compare and contrast. As a genetic counselor, you may want to consider how your practice dwells on topics that your clients hold sacred, and how it does not.

Consider how clients may regard life cycle events and related health care experiences as “spiritual” experiences. For example, a woman may consider childbearing as a “normal way of life,” or as spiritual as “every aspect of our daily life,” or as a sign that the “Spirit of the Lord touched my heart” (Callister & Khalaf, 2010). Illness and death often raise profound spiritual questions for patients. Seriously ill patients, no matter how estranged from religious traditions, may find comfort in these connections (Sulmasy, 2009). Illness raises spiritual questions about meaning, value, and relationship. “Questions about meaning include the ‘Why me?’ questions; questions about the meaning of suffering, life, death, purpose, and afterlife. Questions about value encompass those that illness raises regarding a person’s worth; the value one has (or may not have) when disfigured, dependent, unproductive. Questions about relationship encompass those that illness raises about a person’s relationships, the need for reconciliation and the need to know that one is connected in important ways to family, friends, community, and possibly beyond” (Sulmasy, 2009). Religious and spiritual rituals are often used to cope with distress, even among the non-religious (Bhui, 2010).

Previous studies have shown that doctors and genetic counselors are not entirely comfortable approaching religion and spirituality in health care settings (Cadge et al., 2009; White, 2009; Reis et al., 2007). However, religion and spirituality are important cultural factors that often influence and give meaning to human values, behaviors and experiences that can impact health care (Mueller et al., 2001). “Recent national surveys, for example, show that more than half of Americans regularly pray for their own health

or the health of their family members. More than three quarters of Americans believe that prayer can have a positive effect on people who are ill, and close to three-quarters believe God can cure people given no chance of survival by medical science” (Cadge et al., 2009). For individuals who place emphasis on religion and spirituality, it may be beneficial for health care providers to integrate religious and spiritual assessment into the care plan.

Overview of Religions

While Christianity is the overwhelming majority religion practiced in the U.S., other religions are actively growing. According to United States Census statistics,

- 76% of Americans identified as Christians in 2008 compared to 86.2% in 1990
- 1.17% of individuals identified as Jewish in 2008 compared to 1.79% in 1990
- 0.59% of individuals identified as Muslim in 2008 compared to 0.30% in 1990
- 0.52% of individuals identified as Buddhist in 2008 compared to 0.23% in 1990
- 0.26% of individuals identified as Hindu in 2008 compared to 0.13% in 1990
- 0.32% of individuals identified as a Spiritualist in 2008 compared to 0.19% in 2001 (no data was provided for 1990).

The predicted increase in population diversity in the country in the next fifty years will also increase the religious and spiritual diversity among U.S. residents. To best serve our clients, we can learn the basics of various religions and become comfortable using various tools for religious and spiritual assessment. The genetic counselor personalizes all interactions and adapts tools to match the needs of each client. Religion and spirituality mean different things to each person. These concepts may play a profound role in directing an individual’s complete belief and value system and many everyday behaviors and activities, or they may play virtually no role. For a brief overview of popularly practiced religions, see the CIA World Factbook:

<https://www.cia.gov/library/publications/the-world-factbook/fields/2122.html>

Exercise

What do you know about reincarnation? Use the manual “Religious Traditions and Prenatal Genetic Counseling” by Rebecca Rae Anderson (2002) and/or internet resources to identify 5 distinct religions that incorporate reincarnation as a core belief. Have you ever counseled a client who practices one of these religions?

Exploring Religion and Spirituality with Clients in Health Care Settings

Research reports find a generally positive relation between religiosity and both physical and mental health, including reduced depression and stress, lower blood pressure, lower levels of pain, and higher likelihood of surviving cardiac surgery (Cohen et al., 2000). Providers have additional reasons to take patients’ religious and spiritual beliefs into account when patients consider these beliefs to be important to their health care decisions, and patients want to discuss them with providers in that context. In general, patients want health care providers to address their spirituality. In one study, 65% of

patients felt that it was good for doctors to speak to them about their spiritual beliefs, yet only 10% said a doctor had this type of conversation with them (Puchalski, 2001). Patients may feel that trust in their physician would be strengthened, and that these discussions are warranted especially in the event of serious illness. Puchalski (2001) notes several valuable benefits to understanding a patient's spirituality:

- Spirituality may be a dynamic in the patient's understanding of disease.
- Religious convictions may affect health care decision making.
- Spirituality may be a patient need and may be important in patient coping.
- An understanding of the patient's spirituality is integral to whole patient care.

The Joint Commission for Accreditation of Healthcare Organizations (JCAHO) recognizes the importance of spirituality in health care settings. JCAHO policy states: "For many patients, pastoral care and other spiritual services are an integral part of health care and daily life. The hospital is able to provide for pastoral care and other spiritual services for patients who request them." A hospital chaplain or access to pastoral services is included within the standards for accreditation of all hospitals (JCAHO, 1999). According to the JCAHO, a spiritual assessment should be performed on every patient to identify "at a minimum" the patient's denomination, beliefs, and spiritual practices. Genetic counselors working within hospital systems should therefore be able to identify the institutional standards and resources for pastoral care and spiritual services. Knowing about these overarching institutional resources is a first step. Genetic counselors should also consider how religion and spirituality are addressed within their genetics clinics and genetics departments. In a study of genetic counseling patients, Fick et al. showed that discussion of spirituality is more important to, and comfortable for, patients who identify themselves as "spiritual" than those who do not (2006). This study underscores the need to assess the importance of religion and spirituality with every genetic counseling client.

Genetic counselors may address religion in a limited, structured manner within the prescribed clinic intake forms and routine protocols. Asking the question, "What is your religion?" may seem straightforward, but it is not advised. This blunt question may alienate clients who are atheist, agnostic, or who follow a form of personal spirituality (Tanenbaum, 2009). Or, perhaps this scenario sounds familiar: "We ask all patients if they have any Jewish ancestry since there are certain genetic conditions that are more common when an individual is from a Jewish background." This approach is also not advised. It confines assessment of religion to a narrow and very specific genetic risk factor that tells the counselor he/she should further investigate the family history (i.e., consider Jewish genetic diseases and/or carrier testing). This approach marginalizes the complex cultural and psychosocial information that may be present.

As an alternative to assessing religion through questionnaires or routine questions, genetic counselors can approach the discussion from a less structured general exploration

of the role of religion and spirituality in the client's health care. However, this can be an uncomfortable subject for the provider for many reasons. There may be uncertainty about whether the client's religion would make any difference to his/her health care. Providers may avoid discussions of religion and spirituality because they fear their personal beliefs may conflict with the client's beliefs. Lastly, health care providers may not raise the topic of religion due to the uncertain consequences and sensitive topics that may follow.

Reis et al., 2007 surveyed 127 full members of the NSGC to explore spiritual assessment practices and reactions to a spiritual assessment tool. Fewer than 8.7% of the counselors in this study assessed spirituality in more than half of their genetic counseling sessions. Anderson (2002) states: "My experience as a prenatal genetic counselor has led me to believe that most caregivers are sympathetic to the spiritual dimensions of pregnancy complications, but are uncertain how to broach the topic with their patients. Rather than risking offense, they say nothing, and patients may make the mistaken assumption that their caregivers are indifferent or hostile to their beliefs." Therefore, it is important for genetic counselors to know about available spiritual and religious assessment tools. These tools are meant to help the provider understand the importance of religion and spirituality for the client. They also help the client appreciate the relevance of his/her religious and spiritual beliefs to the health care condition, issue or decision under discussion.

"The standard assessment of coping and support systems provides a natural lead-in to inquiry regarding spiritual resources" (Reis, 2007). Spiritual assessment complements a careful psychosocial history (Puchalski & Romer, 2000). "Spirituality and religious beliefs are embedded in culture" (Fukuyama & Sevig, 2002). "In the management of pregnancy complications, the best interests of the patients often will be embedded in spiritual issues" (Anderson, 2002). Pargament, 2007, p. 203 defines a 'process' of spiritual assessment, which includes setting the stage for spiritual dialogue, initial spiritual assessment, implicit spiritual assessment, and explicit spiritual assessment. Counselor knowledge about religion and spirituality, self-assessment, and communicating openness to learning and sharing with clients are key components to facilitating this process.

Provider Self-Assessment of Religion and Spirituality

In many areas of cross-cultural counseling, self-awareness is an important aspect of providing effective genetic counseling. Self-assessment of religion/spirituality is no exception. Countertransference (unconscious ways of relating to clients based on the counselor's history of relating to others) (Veach et al., 2003) and internal biases arising from personal or professional experiences can impact counseling sessions. Difficulties may emerge when the genetic counselor has an extreme focus on religious issues (too much or too little), avoids addressing religious concerns, feels negative or positive reactions to religion topics, or introduces inappropriate disclosures or interventions (Cashwell & Young, 2005, p. 110). When the counselor feels discomfort, he/she should be attuned to countertransference reactions that can interfere with effective counseling.

These reactions may be minimized by thoughtfully examining one’s own views, reading about religion and spirituality in health care, and discussing personal thoughts and feelings in peer supervision settings.

Miller (2003) suggests questions for psychotherapists to assess their ability to work with clients on matters related to religion and spirituality (p. 56). These questions are also useful for genetic counselors to consider:

1. Can I continue to work with this client given my own countertransference issues?
2. Do I want to continue to work with this client?
3. In working with this client, what limits will I set on how I will address this concern in counseling?
4. In working with this client, how much of my own struggles with these religious views do I need to share?
5. If I decide I cannot work with this client, who will I refer the client to for counseling? How will I bring up the referral with the client?

We suggest several assessment measures that may be particularly suited for self-assessment. Many patient assessment tools are amenable for use as self-assessment tools.

The *Saliency in Religious Commitment Scale* is a short, 3-item tool that provides a measure of the importance an individual places on religiosity. When used for self-assessment, this tool may be helpful to the counselor in achieving greater self-awareness and a better understanding of how their level of religious commitment compares to their clients’. This scale asks the individual to assess the importance and meaning provided by their religious faith, and to consider how faith helps them in decision making. (Roof & Perkins, 1975). An example of a decision making scale in this tool includes: “I seldom/sometimes/often/mostly base important life decisions on religious faith.”

Exercise

Puchalski & Romer (2000) list the following general recommendations regarding taking a spiritual history in medical settings. Using the table below, document the recommendations you currently follow, and the recommendations that are professional goals.

Recommendations	Currently follow? Yes/No	Goal? Yes/No	If a goal, note methods and timeline	If not a goal, list barriers and ways they may be overcome
<i>Puchalski & Romer (2000), p. 131</i>				
1. Consider spirituality as a				

potentially important component of every patient's physical well being and mental health.				
2. Address spirituality at each complete physical exam and continue addressing it a follow up visits as appropriate. In patient care, spirituality is an ongoing issue.				
3. Respect patient's privacy regarding spiritual beliefs; don't impose your beliefs on others.				
4. Make referrals to chaplains, spiritual directors, or community resources as appropriate.				
5. Be aware that your own spiritual beliefs will help you personally and will overflow in your encounters with those for whom you care to make the doctor-patient encounter a more humanistic one.				

To what extent does Amanda apply these recommendations to this genetic counseling session? What could she do to increase the application of these recommendations to this case?

Tools for the Genetic Counseling Session

While including spiritual assessment in genetic counseling sessions is important, the implementation does not have to be daunting. On the contrary, the counselor's approach can be quite simple and targeted. "Genetic counselors need only be concerned with whether their counsees have religious or spiritual beliefs that may influence their ability to interpret and respond to their risks and circumstances, and whether those influences are authentic, reasonable, and beneficial" (White, 2009). Mary T. White suggests by simply

adding one or two questions to the discussion, the genetic counselor can assess whether further tools are needed to help the client through the decision making process. If the client is unresponsive to the few additional questions, no significant time is lost, but if the questions provide a meaningful response that leads to further exploration of religion and spirituality, White argues that the time is well spent (2009).

Suggested questions for the initial interview include:

- Has your [presenting problem] affected you religiously or spiritually [or vice versa]? If so, in what way(s)? (Pargament, 2007)
- Has your religion or spirituality been involved in the way you have coped with your problem? If so, in what way(s)? (Pargament, 2007)
- What helps you get through your tough times? (Mueller et al., 2001)
- What meaning does this illness have for you? (Mueller et al., 2001)
- Is faith (religion, spirituality) important to you in this illness? (Koenig, 2000)
- Is there anything with respect to other areas in your life that we can help you with that will make this process easier for you? (Cadge et al., 2009)
- Are you a spiritual person? (Fick et al., 2006)
- Do you have spiritual beliefs or practices that are important to you? (Tanenbaum, 2009)
- Do you have religious beliefs? (Tanenbaum, 2009)
- Does this raise spiritual issues for you? (Anderson, 2002)
- Do you see yourself as a religious or spiritual person? If so, in what way? (Pargament, 2007)
- Are you affiliated with a religious or spiritual denomination or community? If so, which one? (Pargament, 2007)
- Has your problem affected you religiously or spiritually? If so, in what way? (Pargament, 2007)

The comfort level of the genetic counselor is critical. Each counselor should review and modify existing assessment tools as needed to identify specific words and approaches that he/she can use with ease and authenticity. It may be helpful to practice using some questions in role play settings with colleagues or students before using the questions in clinic. Practicing may help fine tune optimal wording that is consistent with your

personal counseling style. In the following section, we suggest various tools that can be used in genetic counseling and other health care settings to better assess clients' religious and spiritual views and practices.

Client Assessment Tools

See pages 17-26 of the Clinical Tools section of this website for a review of several spiritual and religious assessment tools

(http://www.geneticcounselingtoolkit.com/pdf_files/Cultural%20and%20Spiritual%20Mnemonic%20Tools%2011.06.09.pdf). Consider the similarities and differences among these resources. Each of these tools can be adapted to suit the situation.

- BELIEF
- HOPE
- FICA
- SPIRIT

Exercise

Review the components of **FICA** below. Use and adapt the FICA questions to help Amanda explore Ori and Tal's perspectives on the role of religion in health and illness and their pregnancy.

Faith or beliefs: *What is your faith or belief? Do you consider yourself spiritual or religious? What things do you believe give meaning to your life?*

Importance and Influence: *What influence does it have on how you take care of yourself? How have your beliefs influenced your behavior during this illness? What role do your beliefs play in regaining your health?*

Community: *Are you part of a spiritual or religious community? Is this of support to you and how? Is there a person or group of people you really love or who are really important to you?*

Address: *How would you like me, your healthcare provider, to address these issues in your healthcare?*

Originally referenced:

Puchalski, C., & Romer, A.L. (2000). Taking a spiritual history allows clinicians to understand patients more fully. *Journal of Palliative Medicine*, 3, 129-138.

The *Faith Development Interview Guide* provides an outline for conducting a semi-structured interview with a client to determine the importance he/she places on faith and

religious beliefs. The questions included in this guide may be useful to incorporate into a counseling session to explore a client's beliefs and experiences. The Faith Development Guide (Fowler, 1981) explores:

- life-shaping experiences and relationships (Have you experienced losses or crises that changed your life in special ways?);
- present values and commitments (When you have an important decision to make in your life, how do you go about deciding? Can you share an example?);
- religion (Do you or have you had important religious experiences?); and
- general life review (What gives your life meaning? What makes life worth living for you?).

Reflection Questions

- What psychosocial questions do you currently ask to explore these types of issues? Try to recall client responses and what happened next in the counseling session.
- Which of the questions/ tools noted above are you most likely (and which are you least likely) to integrate into your counseling sessions? Why?

Prayer and other Religious Practices in the Health Care Setting

In a study conducted by the American Pain Society, personal prayer was the most commonly used non-drug method of controlling pain (Puchalski, 2001). Winslow and Winslow, 2001 explored the question of prayer and involvement of nurses in the clinical setting. They suggested five ethical guidelines:

1. In order to provide spiritually respectful care, nurses should seek a basic understanding of patients' spiritual needs, resources, and preferences.
2. Respectful care requires that nurses follow the patient's expressed wishes regarding prayer with the patient.
3. Nurses should not prescribe spiritual practices or urge patients to adopt religious beliefs nor should nurses pressure patients to relinquish their spiritual beliefs or practices.
4. Nurses who care for the spiritual needs of patients should seek to understand their own spirituality.
5. A nurse's participation in prayer with patients should be consonant with the nurse's integrity.

Reflection Questions

- Do these guidelines for nurses resonate with you, personally?
- Do these guidelines for nurses resonate with you, professionally?
- How do these guidelines align with the NSGC Code of Ethics? To access this document, go to:
<http://www.nsgc.org/Advocacy/NSGCCCodeofEthics/tabid/155/Default.aspx>

In many areas within our professional practice, counselors regularly deal with life and death situations. Yet, confining exploration of religion and spirituality to life and death situations may alienate a good number of clients. Decision making about genetic tests, management of genetic conditions, and even the resources you choose to help your clients cope are perceived with the client's unique lens and his/her worldviews on the importance of religion/spirituality. In this case, Ori and Tal turn to prayer in the genetic counseling setting.

- Is the concept of prayer in a genetic counseling setting a comfortable concept to you? Why or why not?
- Does your genetics center or institution have any policies about patients/providers engagement in prayer? If you don't know, how would you find out?
- Does your genetics center or institution have any policies about wearing religious jewelry or displaying other identifiable symbols of religion on your body or in your office? If you don't know, how would you find out?
- At work, do you wear a cross, Star of David, or other jewelry or clothing denoting your religion or faith? If not, why not? If so, have clients ever commented about such emblems? What did they say? How did you feel?
- How often do your clients wear a cross, Star of David, or other jewelry or clothing denoting their religion or faith? Have you ever referred to or commented about such emblems? If so, why? What did you say? How did you feel?

Consider your comfort level with respectfully acknowledging the importance of prayer to your clients. Are you comfortable offering these gestures of respect for clients' need to pray?

- Provide extra time.
- Offer privacy.
- Tolerate silence.
- Listen.

- Bow your head.
- Close your eyes.
- Hold the client's hand.
- Consult with and/or involve a member of the pastoral counseling team.

It is important to be completely truthful with yourself. Which approaches fall within your comfortable personal and professional boundaries? Does the client's religion make a difference to your comfort level? Does your comfort level waiver based on clients' expression of prayer in a religious denomination that you personally practice, one that is very familiar to you, or one that you have never heard of? Does the language in which the prayer is expressed make a difference? When would you refer the client to another genetic counselor?

Challenges to Incorporating Religion and Spirituality into Genetic Counseling

Barriers to incorporating spiritual assessment into genetic counseling identified by Reis et al. included time, insufficient skills, and uncertainty about the role of spiritual assessment in genetic counseling (2007). Tanenbaum notes additional challenges to health care providers' inclination to incorporate religion and spirituality: not knowing how to ask the questions, being unsure of what to do with the information received, and worrying the client doesn't want to talk about religion (2009). There are no specific training requirements in this domain, and given the myriad personal practices of genetic counselors, we should consider the spectrum of current practices. Perhaps sharing experiences will generate future guidelines for training and professional practice. When health care providers talk about religion, opportunities may present to build strong relationships with clients and colleagues, to learn about patient behaviors, and to break down some barriers to health care (Tanenbaum, 2009).

Discussing Testing Options, Interpretation, and Results

This section reviews the process of discussing test options, and interpreting and communicating test results with patients. The genetic counselor assesses the patient's needs and then guides the patient through the genetic counseling process. "Two major genetic counselor activities are providing information and assisting clients in their decision making" (Veach et al., 2003). No matter how common the "indication for referral," each genetic counseling session is unique in terms of patient needs. Some patients may see a genetic counselor without having any idea why they were referred, while other patients may come to the session having already decided to undergo genetic testing. Cultural and religious factors add to the complexity of defining who in the family makes decisions, who to test, who receives the results, as well as assessing the overall implications of genetic test results for family members.

Current genetic counseling job tasks were determined by the American Board of Genetic Counseling as the outcome of a Genetic Counseling Practice Analysis (Hampel et al., 2009). The following is a list of the **Testing Options, Interpretation, and Results Discussion** tasks:

1. TESTING OPTIONS

- a. Explain testing options (pre- and post-natal)
 - i. Diagnostic
 - ii. Screening
 - iii. Predictive (e.g., pre-symptomatic, susceptibility)
 - iv. Research
- b. Identify most informative persons for testing
- c. Explain possible testing outcomes and implications
- d. Discuss potential costs, risks, benefits, and limitations of testing
- e. Help client anticipate the range of emotional effects client and/or family members may experience
- f. Facilitate decision making regarding genetic test
- g. Facilitate genetic testing
- h. Select the test
- i. Select laboratory for testing
- j. Discuss test with laboratory
- k. Identify specimens for testing
- l. Facilitate informed consent
- m. Assess client understanding and response
- n. Modify counseling based on client's understanding and response

2. TEST INTERPRETATION AND RESULTS DISCUSSION

- a. Interpret clinical significance of test results depending on situational variables (e.g., methodology, clinical context, family history, paternity) and literature/resources
- b. Discuss results to include
 - i. Sensitivity and specificity
 - ii. Implications of positive, negative, and/or ambiguous results
- c. Recommend additional testing
- d. Assess client understanding and response
- e. Modify counseling based on client's understanding and response

Testing Options

With rapidly emerging genetic tests available, each offering many potential benefits, genetic testing may soon become part of every routine health care visit. Unlike other medical tests, however, genetic testing can have far-reaching implications for the individual and other family members.

Genetic counselors provide both pre- and post-testing counseling to clients. Pre-test counseling includes informing the client of their various test options, facilitating decision

making, identifying other at-risk family members, and obtaining informed consent. Post-test counseling includes disclosing genetic testing results, providing psychosocial support, and helping the client make a plan for the ‘next steps.’

Genetic counselors engage in an active assessment process by contracting with the client. It is often helpful to start the session by asking clients whether they have thought about genetic testing and if so, how they feel about it. Some clients may assert strong opinions. Other clients may have no opinion or be uncertain as to what genetic testing entails. The genetic counselor listens to the client’s perspectives, and respectfully engages the client in collaborative discourse to best meet his/her needs, while being sure to cover the relevant information. After contracting and providing the relevant medical and genetic information, the genetic counselor then reviews the testing options (diagnostic, screening, predictive, and research) with the client.

Who to Test?

The genetic counselor identifies which, if any, genetic tests are appropriate based on the client’s medical history, family history, and individual needs. For certain tests, the counselor must determine which family member is the most informative person to test. The genetic counselor reviews all medically appropriate testing options, including the option of not having any genetic testing. In reviewing the various testing options, the counselor should not make assumptions about client testing preferences. The session should afford time and opportunities for the client to share his/her perspectives on testing in general, and the implications of each option. Individuals whose family background places more emphasis on the family unit and/or the community than on the individual may perceive testing choices differently than individuals (and counselors) whose Western health care orientation emphasizes preserving patient autonomy.

The genetic counselor explains possible testing outcomes, the implications of genetic testing, and information about costs, risks, benefits and limitations of testing. The pre-test counseling session includes discussion of various possible outcomes of the test. For example, clients undergoing gene sequencing are informed that some people learn they have a variant of uncertain significance, and prenatal clients undergoing a CVS are informed of the small possibility for maternal contamination of the fetal cells, or obtaining no diagnostic information.

The genetic counselor provides anticipatory guidance and helps facilitate decision making regarding genetic testing. In the pre-test counseling session, the genetic counselor helps clients anticipate the range of emotions they and/or their family members may experience. The counselor may use various counseling techniques such as posing scenarios and exploring the client’s feelings and reactions to those scenarios. By providing anticipatory guidance, the clients can begin to consider their thoughts and feelings regarding negative, positive, or inconclusive test results. Anticipatory guidance also includes identifying other at risk family members in the pre-test counseling session and educating the client about how his/her test results may affect other family members. If this topic is not explicitly discussed prior to genetic testing, individuals who test

positive may feel overwhelmed over the responsibility of sharing their genetic test results with other family members (Daly et al., 2001). By identifying at risk family members and discussing the implications genetic testing can have for both the client and his/her family members, the genetic counselor also models communication skills that the client might use when discussing his/her results with the family.

Each client has unique needs and the genetic counselor must identify and clarify those needs, explain the testing process, assess client understanding, facilitate decision making and ensure informed consent. It is important for the genetic counselor to remain unbiased and provide information for all genetic tests available regardless of what decision the counselor feels the client may make.

Test Interpretation

Genetic test results are usually reported by the laboratory in a written document. This document generally includes the following demographic information: name of the patient, the date of birth of the patient, medical record number, the ordering physician, the laboratory that performed the test, the type of test, the results, and whether there were any problems conducting the test. Some test results will also provide a written interpretation of the results and implications for the client's health management. Upon receipt of these results, the genetic counselor checks to make sure that the demographic information is correct, confirming that the results are for this client and that the laboratory performed the specified test (Baker et al., 1998). Sometimes the laboratory must be contacted to seek clarification and/or reinterpretation (Baker et al., 1998). The genetic counselor may need to research the test findings to identify previously reported cases that may help determine clinical management. The counselor undertakes these quality assurance steps to rule out discrepancies and ensure that the correct results are shared with the client.

Test result documents are generally written for the health care provider, and not with the client in mind. Although clients may want a copy of the results for their records, which should be encouraged, the counselor should thoroughly review test result reports with the client to clarify all words and concepts. In addition, the counselor may write a summarizing letter or document to supplement the explanation of test results and that is written at an appropriate level of health literacy for the client.

Test Results

“There should always be a plan for communicating test results” (Baker et al., 1998). During the pre-test counseling session, the genetic counselor and client discuss how test results will be communicated. The counselor shares when the results should be available, and makes a plan with the client to get results by phone, written letter, or in a follow-up visit. Many counselors prefer giving both positive and negative test results in person, the optimal setting for addressing any psychosocial issues. In certain time-sensitive situations, it may be necessary for the genetic counselor to disclose the results via telephone and also schedule a follow-up visit. For example, it is appropriate to follow up

in this manner on CVS test results that will be used to making decisions about continuing a pregnancy (Baker et al., 1998). Counselors should be mindful of religious practices or holidays that do not permit certain patients to talk by phone or come for a visit, such as on the Jewish Sabbath.

An awareness of general cultural norms is helpful, but these norms will not describe the needs and practices of any individual family. It is good practice to ask family members about their preferences for communicating with them (Levetown, 2008). Questions genetic counselors may ask (modified from Levetown, 2008) include:

- “How should I give your family information about...the patient...or the genetic test results?”
- “With whom do I share the information?”
- “Who generally makes decisions in your family?”
- “Are there topics that should not be directly addressed in your family?”

Providing repeated opportunities for clients to ask questions, allowing for long periods of silence in the session, inviting family members to the session and time to consult with others on decisions, and providing written summaries or tapes of conversations may facilitate client understanding through sharing information with others (Levetown, 2008).

Communicating “negative” test results may seem like a straightforward task. Upon closer examination, however, these test results may present unique challenges and may not be perceived by a client as good or welcome information (Veach et al., 2003). The genetic counselor should be extremely sensitive when phrasing test results. Stating that the test came back “normal” could imply that there is no need to worry about anything. To the genetic counselor, it may seem obvious that genetic tests have limitations, but this should be clearly conveyed to the client (Veach et al., 2003). Each client has unique needs and responses with respect to genetic test results. The genetic counselor can anticipate some of these psychosocial issues in the pre-test counseling session by using scenarios and hypothetical questions.

Communicating “positive” test results also poses unique challenges. “Abnormal” test results may also not evoke the expected emotions. While many clients respond by crying, showing anger, denying, etc., some clients will feel relief to finally have an answer to their medical problems (Veach et al., 2003). To a client who has seen many specialists and has found no cause to their health problems, receiving news of having a genetic condition may be welcomed. The genetic counselor should never assume that he/she knows how the client will respond to test results, but he/she should always be prepared to provide psychosocial support. When communicating undesired test results to clients, it is important to speak slowly, use pauses, and convey information in chunks so to help the client absorb the news (Veach et al., 2003).

The counselor may communicate abnormal results to a client using a modification of the 6-step protocol suggested by Buckman (1992). The affective relationship between the informant and the client impacts the client's ability to process bad news (Levetown, 2008). Clients often prefer the health care provider to convey less information and place more emphasis on establishing trust. As a general rule, the counselor will rely heavily on using basic counseling skills and providing support.

- Empathy... "I can see you that were not expecting this." "You had great hopes for your baby."
- Unconditional positive regard: "You did everything possible to have a healthy baby. There are lots of things we don't understand about why some chromosome abnormalities occur."
- Genuineness: "I am so sorry to have to share this information with you. I truly wish that the news would have been different."
- Support: "I am here for you, today, next week, and for as long as I can be helpful. This is a lot to absorb. You don't have to do anything right now."

The genetic counselor should not provide false reassurances or discourage the client from sharing his/her emotions. If a client is having difficulty coping with the test results, it may be useful to schedule another counseling session to give the client time to absorb the information and seek comfort in family and friends. Any follow-up information regarding what the test results mean for medical management or risks to other family members will be more useful when the client has had time to process the abnormal test result.

Stereotypes and Generalizations

Geri-Ann Galanti is a well-known expert in cultural competence who describes the difference between using stereotypes versus generalizations in interpersonal interactions. These differences are relevant to the process of identifying candidates for genetic testing, discussing testing options, and communicating genetic test results. Dr. Galanti describes stereotypes as ending points, as they stifle the health care provider's interactions with culturally diverse clients. For example, a genetic counselor may realize that none of the Hispanic women she counseled in the past year underwent diagnostic testing. The counselor might then assume that Hispanic women in general are not interested in diagnostic testing options. Therefore, the counselor glosses over these options with her Hispanic clients. In this example, the counselor's assumptions hinder the care she provides. The counselor hasn't explored individual client preferences and her Hispanic clients haven't been given full information.

In contrast, a counselor can use generalizations about a person's country of origin, religion, or other factors to create a new beginning. The counselor can use this general information as a platform for further inquiry and exploration of each client's unique perspectives, preferences, values and beliefs.

The distinction between using stereotypes and generalizations is particularly important when working with culturally diverse clients, but it applies to all interactions. See the following link to read more from Dr. Galanti's excellent book, [Caring for Patients from Different Cultures](#):

http://books.google.com/books?id=hEvy839Xs6MC&pg=PA7&lpg=PA7&dq=galanti+stereotype+vs+generalization&source=bl&ots=R6DDIURT0T&sig=MLfvKANJSXXz2ceIzFZ-Rrx09qg&hl=en&ei=LOG3TLbQOIa8IQfPIJHBDA&sa=X&oi=book_result&ct=result&resnum=1&ved=0CBYQ6AEwAA#v=onepage&q&f=false

By using generalizations as a knowledge base, the counselor is empowered to make culturally-sensitive educated guesses. The counselor should ask if certain specific values, beliefs or practices that she has learned about apply to this client. The counselor's inquiries should be genuine, humble, and tentative. If the genetic counselor feels he/she may offend the client by bringing up certain topics, a statement of full disclosure can preface the discussion. "I understand that not all the testing options may seem appropriate for your circumstance, but it is my job to make sure you are fully aware of all your options before making any decisions. If any test option is definitely not an option, please let me know and I can limit the discussion of it" (Veach et al., 2003).

Facilitating Decision Making

Decision making is a complex construct that lies at the heart of most genetic counseling encounters. Values, beliefs, previous experiences, information, support systems, family background, personality, risk perception, perceived severity, social expectations, cultural roots, financial status, emotional preparation, real and perceived options, personal goals, and religion are a few of the many salient factors that individuals may consider when making decisions. Decisions may be complex, heart-wrenching, and far-reaching. Often, risks and events are perceived by clients as binary, that they either happen or they don't. When an unwanted event occurs, the genetic counselor may wish to explore *why* certain options and decisions seem best to the clients rather than try to understand their decision as correlating to specific genetic and risk information. Message framing, and the degree of focus on certain topics or options over others, have been shown to influence client decisions (Salkovskis et al., 1999). Decisions are strongly influenced by focusing on negative aspects of test results and immediate harms.

The genetic counselor's role in helping patients in the decision making process is generally regarded as providing impartial and nondirective counseling. Regarding genetic testing of any kind, pre-test counseling provides an important opportunity for the genetic counselor to provide extensive information without polarizing the issues negatively or positively. Counseling interventions such as role plays, role reversal and using scenarios can help clients consider the effects of testing options and possible results on themselves and their families.

Genetic counselors generally accept that nondirective counseling with information as well as guidance and advice gained from listening to a client is usually helpful when clients struggle with or feel overwhelmed by the decision making process. By taking this approach, the counselor becomes a source of support, as well as a trusted partner with whom the client can explore ideas, outcomes, fears, and scenarios about options and possible outcomes. In the context of working with religious/spiritual families, the genetic counselor might ask the client, “Do you have religious concerns about these options?” and/or “Would you like some time to consult with a pastor about this?” (Anderson, 2002). These questions legitimize the uncertainty families may feel about their situation, and facilitate reaching out to their faith community.

Anderson (2002) states: “Families whose choices diverge from those suggested by denominational doctrine will benefit from the exercise of assessing their moral reasoning in light of the precepts of their faith communities. Although it may appear ‘easier to ask forgiveness than to ask permission,’ ultimately, facing the issues squarely will provide greater opportunity for reconciliation, healing and spiritual growth.” Cure is not possible for many genetic conditions, but there is always room for healing. Healing may be experienced as an acceptance of the condition and peace with the situation. This healing may be considered spiritual (Puchalski, 2001).

Summary: Genetic Testing and Religion/Spirituality

In this case, Amanda was quiet when she walked into the room, allowing Ori and Tal private time. However, Amanda then focused on **her** personal agenda of communicating the diagnostic information to the couple as soon as possible. Indeed, Amanda did not seem to know how to respond to the couple when they shared that they had been praying. Similar to health care providers who shy away from inquiries that they fear may take them to “the brink of turbulent and unfamiliar waters” (Cohen et al., 2000), Amanda provides inadequate care. Given the serious information Amanda needs to communicate, perhaps she could have spent more time listening to and developing trust with the couple. Time may seem short, but “few pregnancy-related procedures are so urgent that time cannot be made for consideration of the faith implications of therapeutic options” (Anderson, 2002).

Perhaps Amanda could have explored the couple’s perspectives on prayer before launching into the diagnostic information. We do not know about Amanda’s personal viewpoints on religion/spirituality, or whether she has had previous experiences with prayer in the genetic counseling setting. One might argue, however, that Amanda has a moral obligation to attend to the couple’s spiritual needs within the framework of providing client-centered, respectful, and supportive genetic counseling. Sulmasy (2009) asserts that “when the patient is religious and the health care professional is not, the physician should take the initiative to make inquiries about the patient’s religious beliefs and be supportive and perhaps even to be encouraging of that patient’s beliefs. When the health care professional is religious and the patient is also religious, then both should be able to talk about religion in relationship to healing.”

Fowler (1981) suggests a question that may be helpful to engage clients on the topic of prayer: “When you pray, what do you feel is going on when you pray?” This question and the subsequent discussion might have helped Amanda better understand the Ori and Tal’s perspectives, fears, beliefs, and coping mechanisms. If she had known that the news of the baby’s abnormalities is what they fear most, she could have used additional counseling interventions to help them prepare to receive the unwanted news. Perhaps Amanda could have asked, “Could you share how prayer brings you comfort in difficult times?” or “In the past, how has your religion helped you through tough times?”

After that, what should Amanda do?

Sulmasy (2009) offers advice for physicians who uncover profound spiritual concerns and are uncertain about what to do next. Sulmasy suggests “the clinician can simply say, “It seems that these matters are serious and important. I’m very glad that I asked. Now we need to figure out how best to help you. I think it would be beneficial if a member of our pastoral care staff, Reverend Jones, were to come to see you. If it is OK with you I will let her know that we’ve had this conversation...” Rather than abandoning the couple, Amanda could have made this suggestion and welcome the expertise of a member of the clergy or a pastoral counselor. Ideally, the genetic and the pastoral counseling professionals will continue to work together with Ori and Tal to explore the couple’s thoughts about the pregnancy, next steps, and their future. “Families who are hesitant about their choices may find their paths made clear while reviewing their denomination’s doctrines with a spiritual leader” (Anderson, 2002). The genetic counselor should offer information and support, including grief, loss, and fetal hospice resources as appropriate.

Extended explicit discussions on religion and spirituality will generally not fall into the realm of the genetic counseling provider-client relationship. In depth elicitation of the client’s ‘spiritual story’ is best left to the pastoral counselor on the team. The Regent University Hope Research Project conducted by Davis et al. (n.d.) suggests four situations in which an in-depth, follow-up assessment of an individual’s religious and spiritual system is always warranted:

- 1) When religion and/or spirituality seems clinically relevant to the client/couple’s presenting problems and treatment goals;
- 2) When religion and/or spirituality is one of the primary informants of the client/couple’s worldviews;
- 3) When religion and/or spirituality appears likely to either facilitate or hinder therapeutic progress; and
- 4) When religion and/or spirituality is significantly impaired by the client/couple’s presenting problems.

When further religious and spiritual assessment is warranted or implied, topics to evaluate include, but are not limited to: metaphysical worldview, history, affiliation (past

and current), experiences (past and current), values, meaning, beliefs, preferences, orthodoxy, deity/supreme being image(s), practices, value-lifestyle congruence, concerns, needs, struggles, coping style, prayer style, orientation (intrinsic/extrinsic), health, well-being, identity, maturity, and support system (Davis et al., n.d.).

Cohen et al. (2000) point out that due to disparities of power that operate in health care settings, it is important for providers to set ethical boundaries on their inquiries into patients' religious concerns. Providers should not give patients the impression that the availability and quality of their treatment depends on whether they embrace certain religious commitments. Involving pastoral counseling as part of the care team allows patients to discuss their fundamental convictions freely. In some centers, pastoral counselors with expertise in genetic conditions, or genetics professionals with pastoral counseling training will be available. As the need for genetic services increases, there will be a commensurate need for more practitioners who are able to provide "pastoral genetic counseling" (Abdella, 2000). Inadequate numbers of pastoral counselors with sufficient education in clinical genetics currently exist (Boyle, 2004). Genetic counselors will likely need to reach out and create shared learning opportunities with local pastoral counseling departments and training programs. There are many potential topics suitable for case conferences, seminars, and invited lecture series to advance learning and skills development for practicing clinicians and trainees from both disciplines.

Amanda's reasons for not exploring spirituality and religion with Ori and Tal are unknown to us. She may have felt uncomfortable approaching the subject. She may have been uncertain that she was the best person to speak with Ori and Tal about religion and spirituality. Or, she may have felt that discussion of religion/spirituality would not affect the outcome of her session. Regardless of the reason(s) why Amanda did not discuss religion and/or spirituality, the lack of conversation about religion and/or spirituality was detrimental. Perhaps Amanda could have encouraged this couple to tell her more about their baby's spirit, Ori's father, and their hopes and wishes for this baby. This approach could help Amanda build trust to facilitate an open discussion of the couple's thoughts about Trisomy 13.

While religion and spirituality may be a challenging topic to explore, this case demonstrates that not exploring the topic makes the session even more difficult. Ideally, the genetic counselor will use one or more examples from this case to help facilitate discussion and exploration of religious and spiritual issues in genetic counseling sessions. When the client places strong emphasis on religion and/or spirituality and the genetic counselor is uncertain how to best incorporate them into the session, a referral to a hospital chaplain or a trusted member of the clergy in the community will always be appropriate.

Religion, spirituality, and genetic counseling are ideal topics for peer supervision sessions. It may be difficult to process the events of specific sessions due to blind spots caused by countertransference. The following are potential topics for discussion in a peer supervision setting. The questions should be considered privately by each participant before the group discussion.

1. Have you ever discussed religion/spirituality with your genetic counseling colleagues? If so, what was the context for this discussion? If not, would this discussion be of interest? Why or why not?
2. How often are you involved in genetic counseling sessions where the name of a divine being is implicated as a cause or a punishment for a genetic condition or a situation? Are there specific situations in your practice that tend to lead to discussions of a divine being? Would you like to see these topics arise in clinic more, or less, frequently? Why?
3. How does gaining a deeper understanding of patients' cultural and religious background enable genetic counselors to deliver more effective health care? Can you share any case examples?

Cultural Competence

- Continue to learn about organized religions and other sources of meaning and hope.
- Explore rituals and beliefs on fetal and neonatal loss, grief and mourning in different religions and cultures.
- Be aware that personal feelings on religion and spirituality can help a counselor gain clarity and insight. On the other hand, these feelings can blind a counselor from appreciating clients' perspectives, beliefs, and practices.
- Review, adapt and use religious and spiritual assessment tools to determine the role of these factors in clients' worldviews on health, illness, and decision making.
- Be client-centered. Get engaged with clients who explicitly or implicitly indicate the importance of religion or spirituality. This is an opportunity to learn!
- If you freeze and don't know what to say, take a minute to recover. Use silence and maintain open, interested body language. Let the client take the next step.
- If you avoid or ignore religion/spirituality in genetic counseling sessions, refer clients to a colleague. Define a plan for increasing your confidence and competency.
- Use your institutional and local resources. Hospital chaplains and local religious leaders should be integral members of the genetics services team. Proactively engage these clergy in providing patient-specific support and pastoral counseling. Collaborate with and refer clients to indigenous healers when appropriate (Fukuyama, 2002).

- Participate in peer supervision discussions to explore your thoughts and feelings about religion and spirituality in genetic counseling sessions.

Resources

- Spirituality and Religion in Medicine, Drexel University
<http://webcampus.drexelmed.edu/religion/default.asp>
- Center for Religious Tolerance
<http://www.c-r-t.org/index.php>
- Native American Spirituality-Manataka American Indian Council
http://www.blueskywaters.com/page_82.pdf
-
- American Native Spirituality
- <http://www.tahtonka.com/spirituality.html>

Books

Anderson, R.R. (2002). *Religious Traditions and Prenatal Genetic Counseling*. Munroe-Meyer Institute, University of Nebraska Medical Center, Omaha, NE.

Buckman, R. (1992). *How to Break Bad News: A Guide for Health Care Professionals*. The Johns Hopkins University Press, Baltimore, MD.

Callister, L.C. & Khalaf, I. (2010). Spirituality in Childbearing Women. *Journal of Perinatal Education*, Vol. 19, No. 2, 16-24.

Cashwell, C.S. & Young, J.S. (2005). *Integrating Spirituality and Religion Into Counseling*. American Counseling Association, Alexandria, VA.

Doka, K.J. & Tucci, A.S. (2009). *Diversity and End-of-Life Care*. Hospice Foundation of America, Washington, DC.

Fowler, J.W. (1981). *Stages of faith: the psychology of human development and the quest for meaning*. San Francisco: Harper and Row.

Galanti, Geri-Ann. (2008). *Caring for Patients from Different Cultures*. University of Pennsylvania Press, Philadelphia, PA.

LaDuke, W. (2005). *Recovering the Sacred: The Power of Naming and Claiming*. South End Press, Cambridge, MA.

Miller, G. (2003). *Incorporating Spirituality in Counseling and Psychotherapy: Theory and Technique*. Wiley, Hoboken, NJ.

Pargament, K.I. (2007). *Spiritually Integrated Psychotherapy: Understanding and Addressing the Sacred*. The Guilford Press, New York, NY.

Tanenbaum Center for Interreligious Understanding. (2009). *The Medical Manual for Religio-Cultural Competence*. New York, NY.

Veach, P.M., LeRoy, B.S. & Bartels, D.M. (2003). *Facilitating the Genetic Counseling Process: A Practice Manual*. Springer-Verlag, NY.

References

Abdella, P.M. (2000). Genetic Disorders and Pastoral Care. *America*, November 25, p. 7-11.

Anderson, M.R., Moscou, S., Fulchon, C., & Neuspiel, D.R. (2001). The Role of Race in the Clinical Presentation. *Family Medicine*, 33, No. 6, p. 430-434.

Bhui, K. (2010). Culture, religion and health care. *International Journal of Integrated Care*, 10. 57-59.

Boyle, P.J. (2004). Genetics and Pastoral Counseling. In: *Second Opinion*, 11, April. The Park Ridge Center for Health, Faith and Ethics, Park Ridge, IL.

Cohen, C.B., Wheeler, S.E., Scott, D.A., Edwards, B.S., Lusk, P. & the Anglican Working Group in Bioethics. (2000). Prayer as Therapy. Hastings Center Report, May-June, p. 40-47.

Davis, E.B., Kemp, H. & Engelbert. (n.d.) Religious/Spiritual Assessment with the Hope-Focused Couples Approach. Regent University Hope Research Project.
http://hopecouples.yolasite.com/resources/Strategy_Guides/Religious%20Spiritual%20Assessment%20within%20the%20HFCA.pdf

Fick, J, Peach, E., Adams, K., Warren, N.S. (2006). Discussing Spirituality in Genetics Clinic: Patient Perspectives. Poster, National Society of Genetic Counselors Annual Education Meeting, Nashville, TN.

Fukayama, M.A. & Sevig, T.D. (2002). Spirituality in Counseling Across Cultures: Many Rivers to the Sea. In: *Counseling Across Cultures*, 5th Edition. Paul B. Pedersen, Juris G. Draguns, Walter J. Lonner, & Joseph E. Trimble, Eds. pp. 273-295.

Hampel, H., Grubs, R.E., Walton, C.S., Nguyen, E., Breidenbach, D.H., Nettles, S., et al(2009). Genetic Counseling Practice Analysis. *Journal of Genetic Counseling*, 18(3), 205-216.

- Hunt, L.M. & Megyesi, M. (2008). The ambiguous meanings of the racial/ethnic categories routinely used in human genetics research. *Social Science & Medicine*, 66, 349-361.
- Joint Commission on Accreditation of Healthcare Organizations (JCAHO) Comprehensive Accreditation Manual for Hospitals (CAMH): The Official Handbook (update 3) Oakbrook Terrace, Ill: JCAHO; 1999. Patient rights and organization ethics; pp. R1–15.
- Levetown, M. & the Committee on Bioethics. (2008). Communicating with Children and Families: from Everyday Interactions to Skill in Conveying Distressing Information. *Pediatrics*, 121 (5): e1441-60.
- Mueller, P.S., Plevak, D.J., & Rummans, T.A. (2001). Religious involvement, spirituality and medicine: Implications for clinical practice. *Mayo Clinic Proc*, 76, 1225-1235.
- Puchalski, C.M. (2001). The role of spirituality in health care. *Proc (Bayl Univ Med Cent)*, 14(4), 352-357.
- Puchalski, C. & Romer, A.L. (2000). Taking a Spiritual History Allows Clinicians to Understand Patients More Fully. *Journal of Palliative Medicine*, Vol. 3, No. 1, 129-137.
- Reis, L.M., Baumiller, R., Scrivener, W., Yager, G., Warren, N.S. (2007). Spiritual Assessment in Genetic Counseling. *Journal of Genetic Counseling*, Vol. 16, No. 1, 41-52.
- Roof, W.C. & Perkins, R.P. (1975). On conceptualizing salience in religious commitment. *Journal for the Scientific Study of Religion*, 14, 111-128.
- Salkovskis, P.M., Dennis, R. & Wroe, A.L. (1999). An Experimental Study of Influences on the Perceived Likelihood of Seeking Genetic Testing: “Nondirectiveness May Be Misleading. *Journal of Psychosomatic Research*, 47, 5; 439-447.
- Sulmasy, D.P. (2009). Spirituality, Religion, and Clinical Care. *Chest*, Vol. 135, No. 6.
- White, M. (2009). Making Sense of Genetic Uncertainty: The Role of Religion and Spirituality. *American Journal of Medical Genetics*, 151C (1): 68-76.
- Winslow, G.R. & Winslow, B.W. (2003). Examining the Ethics of Praying with Patients. *Holist Nurs Pract*, 17(4):170-177.

Assessment and Evaluation Questions: Testing Options, Interpretation, and Results: Spirituality and Religion in the Genetic Counseling Setting

1. True or False
The letters in the mnemonic FICA stand for Faith, Income, Coping, Acculturation
2. True/False
Spiritual assessment and psychosocial assessment are complementary, overlapping client assessments.
3. True/False
The words religion and spiritual share the same Latin root word.
4. True/False
An effective spiritual assessment requires the health care provider to ask a substantial number of questions that typically require significant time.
5. True/False
Geri-Ann Galanti suggests using generalizations to enhance interpersonal interactions.
6. True/False
It is important for providers to set ethical boundaries on their inquiries into patients' religious concerns.
7. True/False
Client spiritual assessment should be done by specially trained members of the pastoral counseling team and not by genetic counselors.
8. True/False
Prayer is a commonly used method of pain control.
9. True/False
JCAHO requires a spiritual assessment in every patient encounter.
10. True/False
If a counselor thinks that bringing up the topic of religion will offend the client, it is best not to bring it up and risk damaging rapport.

The following questions are for CEU learners only:

1. I feel I have achieved the following objective as a result of this learning activity:

Explain the steps involved in discussing testing options, interpretation, and results.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

2. I feel I have achieved the following objective as a result of this learning activity:

Elicit and interpret individual and family experience, behaviors, emotions, perceptions and attitudes that may clarify clients' religious and spiritual beliefs and values.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

3. I feel I have achieved the following objective as a result of this learning activity:

Increase awareness of factors that contribute to decision making in genetic counseling settings.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

4. I feel I have achieved the following objective as a result of this learning activity:

Incorporate assessment and discussion of religion and spirituality in genetic counseling sessions.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

5. I feel I have achieved the following objective as a result of this learning activity:

Facilitate decision making in an unbiased, non-coercive manner.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

6. Please rate the overall effectiveness of this case in promoting learning.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

7. Please rate the overall quality of this case.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

8. The content of this case was presented without bias of any commercial drug or product.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

9. The technology used was appropriate and effective.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

Disclaimer

The purpose of the Genetic Counseling Cultural Competence Toolkit (GCCCT) is to improve the delivery of culturally responsive, client-centered genetic counseling to diverse populations and to reduce health disparities. The GCCCT is an educational resource; any suggestions do not define the standards of clinical or educational practice. All cases and scenarios are hypothetical. The JEMF, NSGC and Nancy Steinberg Warren, MS, CGC will not be liable for any medical or psychosocial applications connected with the use of or reliance upon any information obtained from this website or associated links and resources.

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