
Original Research

Spiritual Assessment in Genetic Counseling

Linda M. Reis,^{1,2,6} Robert Baumiller,³ William Scrivener,⁴
Geoffrey Yager,⁵ and Nancy Steinberg Warren^{1,2}

Published Online: 3 February 2007

One hundred and twenty seven full members of the National Society of Genetic Counselors participated in this study exploring current spiritual assessment practices of genetic counselors and reactions to a spiritual assessment tool. While 60% of genetic counselors reported they had performed a spiritual assessment within the past year, fewer than 8.7% of these counselors assessed spirituality in more than half of their sessions. Counselors reporting high perceived relevance of spiritual assessment performed an assessment more frequently than those reporting a low perceived relevance. Barriers to spiritual assessment included lack of time, insufficient skills, and uncertainty regarding the role of spiritual assessment within genetic counseling. Almost two-thirds of counselors expressed that having a spiritual assessment tool would increase their ability to elicit relevant information. These data suggest a need for increased training regarding the methods for and relevance of spiritual assessment in genetic counseling. Recommendations for future directions of research are explored.

KEY WORDS: spirituality; genetic counseling; spiritual assessment; HOPE tool; religion; psychosocial; genetics.

INTRODUCTION

The past 40 years has seen a renewed interest in spirituality within modern culture (Bash, 2004). While definitions of spirituality vary, they generally include a focus on a sense of meaning and purpose derived from a relationship with God or a higher being, self, and others (Greenwald and Harder, 2003; Hodge, 2001; Koenig, 2002; McVay, 2002; Treloar, 1999). Anandarajah and Hight (2001) identified three aspects of spirituality: cognitive/philosophical, experiential/emotional, and behavior. The first, cog-

nitive/philosophical, involves the beliefs and values that guide daily life as well as the search for meaning, purpose, and truth in life. The second, experiential/emotional, regards the feelings of hope, love, connectedness, inner peace, comfort, and support sustained by relationships and connections with self, community, environment, nature, and the transcendent. The third aspect, behavior, consists of the external manifestations of individual spiritual beliefs and inner spiritual state.

Recent polls demonstrate significant public interest in having spiritual topics addressed by health care providers. Approximately 87% of Americans identify religion as being at least fairly important in their lives with 58% identifying it as very important (Gallup, 2002). Studies involving patients who were seriously ill found that high proportions of participants felt that a physician should consider (77%) or discuss (53%) a patient's spiritual needs (Kaldjian *et al.*, 1998; King and Bushwick, 1994). Additionally, 66% of adult outpatients at the Hospital of the University of Pennsylvania indicated that a

¹Genetic Counseling Program, College of Allied Health Sciences, University of Cincinnati, Cincinnati, OH.

²Division of Human Genetics, Cincinnati Children's Hospital Medical Center, Cincinnati, OH.

³Departments of Biology and Philosophy, Xavier University, Cincinnati, OH.

⁴Director of Pastoral Care, Cincinnati Children's Hospital Medical Center, Cincinnati, OH.

⁵College of Education, University of Cincinnati, Cincinnati, OH.

⁶Correspondence should be directed to Linda M. Reis P.O. Box 1997, MS # 716, Milwaukee, WI 53201; e-mail: lreis@chw.org.

physician's inquiry about spiritual or religious beliefs would strengthen the patient's trust in the physician (Ehman *et al.*, 1999).

Research in the past 20 years increased our understanding of the connections between spirituality, religion, and health (Mills, 2002). Spirituality has positive effects on mental, physical, and emotional health including coping ability, self-esteem, and social support systems (Anandarajah and Hight, 2001; Hodge, 2001; Koenig, 2002; Thoresen and Harris, 2002; Treloar, 1999). In addition, religious and spiritual beliefs can profoundly influence medical decision-making. In one study of ambulatory adult patients seen in a pulmonary clinic, 45% of participants indicated that religious beliefs would influence their medical decision-making if they became gravely ill (Ehman *et al.*, 1999). A study of individuals at high-risk for breast cancer found that a patient's self-perceived spirituality, assessed before receipt of genetic counseling, influenced her decision-making regarding testing of the BRCA1 and BRCA2 genes after counseling (Schwartz *et al.*, 2000).

A prominent author in the area of spirituality and healthcare, Harold Koenig, stated, "neglecting the spiritual dimension is just like ignoring a patient's social environment or psychological state, and results in failure to treat the whole person" (Koenig, 2002, p. 6). Koenig (2002) identifies three goals of spiritual assessment in healthcare. First, the provider should learn about a patient's religious beliefs, especially those that pertain to medical care. Second, an understanding of the ways a patient's religious or spiritual beliefs aid or hinder their coping with illness should be gained. Third, any spiritual needs of the patient should be identified. By performing a spiritual assessment, the health care provider communicates respect for the patient's spirituality and obtains information about the patient's support system. Spiritual assessment within a health care setting may enhance the patient's coping, influence patient compliance with medical management by recognizing beliefs which may interfere with treatment, and identify individuals who may benefit from a referral for pastoral counseling (Koenig, 2002).

Various spiritual assessment tools are reported in the literature for use by health care providers (Anandarajah and Hight, 2001; Hall and Edwards, 2002; Hatch *et al.*, 1998; Hodge, 2001; Maugans, 1996; Puchalski and Romer, 2000; Vandenbrink, 2001). Physicians Gowri Anandarajah and Ellen Hight developed the HOPE tool for spiritual assessment to help medical students, residents, and practicing

physicians learn to incorporate spiritual assessment into their clinical practice (Anandarajah and Hight, 2001). The tool involves a series of questions assessing four general spiritual topics, namely sources of hope, meaning, comfort, strength, peace, love, and connection (H), the role of organized religion (O), personal spirituality/practices (P), and effects on medical care and end-of-life issues (E) (Appendix 1). This tool is patient-centered, utilizes an interactive conversational style, introduces the topic of spirituality gradually by beginning with indirect aspects of spirituality, provides an opportunity for clients to decline further exploration, and is respectful of most religious traditions' framework of spirituality (Anandarajah and Hight, 2001; Koenig, 2002). Not every question within the HOPE tool is meant to be included within a spiritual assessment; health care providers can select which questions are appropriate for use with a particular client.

Despite the increased awareness regarding the link between health care and patient spirituality, the role of spiritual assessment within genetic counseling has not been investigated. The primary aim of this study was to explore current spiritual assessment practices, including identification of barriers, within genetic counseling. In addition, the study examined the feasibility and appropriateness of the HOPE tool as a model for spiritual assessment within genetic counseling by assessing counselors' perceived relevance of and comfort with questions from each of the four spiritual topics addressed (H,O,P,E).

METHODS

Sample and Procedure

A convenience sample of full members of the National Society of Genetic Counselors (NSGC) was included in this cross-sectional study. The email addresses of a random sample were obtained from the NSGC directory. An initial request for participation was sent by email to 765 full members, describing the study and providing a link to complete the online survey. The initial request informed participants that the survey was anonymous and that consent was assumed with participation. A reminder email was sent to each participant approximately two weeks after the initial contact. Approval for this study was obtained from both the Cincinnati Children's Hospital Medical Center and the University of Cincinnati institutional review boards.

Measures

The survey instrument was a self-administered online questionnaire with four sections. The instrument consisted of 32 questions including Likert scales, yes/no questions, multiple response lists, and open-ended questions. The questionnaire was developed by a multidisciplinary team including professionals in genetic counseling, mental health counseling, clergy, and chaplaincy to ensure content validity. Various spiritual assessment tools were reviewed by the team with regards to genetic counseling practice and the HOPE tool was chosen for the reasons noted above. The questionnaire was piloted with one genetic nurse specialist for clarity and understandability.

The first section of the questionnaire assessed the attitudes and practices of each participant regarding spiritual assessment. Respondents were asked to indicate the frequency with which they assess spirituality as well as their perceived importance of and relative comfort with spiritual assessment using a five-point Likert scale (with 1 = not at all, 2 = slightly/mildly, 3 = moderately, 4 = very, and 5 = extremely). Counselors were asked to choose from a list of potential reasons for assessing, or not assessing, spirituality in a session. Participants could provide additional reasons through an open-ended response question.

The second section of the questionnaire presented examples of questions taken from the HOPE spiritual assessment tool (Anandarajah and Hight, 2001). The questions from each of the four topics (as described above) were placed in random order. For each question, participants were asked to indicate first, whether the question would be relevant in some genetic counseling sessions (i.e., yes or no) and second, the extent to which they would feel comfortable asking the question within a session (i.e., 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, or 5 = strongly agree).

The third section of the questionnaire included follow-up questions to determine the effect of the introduction of an assessment tool on genetic counselors' attitudes toward spiritual assessment. Participants were asked to indicate whether having a spiritual assessment tool would increase their comfort and ability in assessing client spirituality (i.e., 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, 5 = strongly agree) and whether they intended to incorporate the HOPE tool into future sessions (i.e., 1 = definitely won't, 2 = probably

won't, 3 = might, 4 = probably will, 5 = definitely will). An open-ended question was provided for comments. The fourth section requested demographic information from participants including years of practice, gender, and religious affiliation. In addition, participants were asked to self-identify their own spirituality using a five-point Likert scale (i.e., 1 = not at all spiritual, 2 = mildly spiritual, 3 = moderately spiritual, 4 = strongly spiritual, and 5 = very strongly spiritual).

Data Analysis

Statistical analysis was performed using SPSS 12.0 for Windows®. Descriptive statistics including frequency, mean, and mode were calculated for each question in sections 1, 3, and 4. Chi-square analysis was performed to compare the responses of genetic counselors who had performed a spiritual assessment in the past year to those who had not. Responses were also analyzed by years of practice, self-perceived spirituality, and religious affiliation. A *p* value of < .05 was used as the cutoff for statistical significance.

The responses in section 2 were totaled by topic addressed (i.e., H,O,P,E) to provide a summative score for each topic area. There were four questions each for topics H, P, and E; five questions were included for topic O. Responses to two of the questions within topic O were statistically similar; one of these questions was excluded from the analysis so that the summative score for each topic could be compared. This exclusion did not significantly change the average score for topic O. The summative scores were then compared using the Friedman test, which calculates the mean rank of each topic. This test was chosen as it was felt that participants' perceived relevance/comfort ranking for one topic would be related to their perceived relevance/comfort ranking for the others. The summative scores were compared to determine each respondent's ranking of topics (least relevant/comfortable to most relevant/comfortable); these rankings were averaged to determine the overall ranking of each topic. Again, a *p* value of < .05 was used as the cutoff for statistical significance. The topics were then compared pair-wise using the Friedman test to examine differences between rankings. A total of 6 pair-wise comparisons were performed (H:O, H:P, H:E, O:P, O:E, P:E); a Bonferroni adjustment was used to determine the *p* value of < .008 (.05/6) used as the cutoff for statistical significance.

Table I. Demographic Characteristics of Sample Population

	Total Sample: $N = 120^a$	
	<i>n</i>	%
Years of Practice		
1–5 years	55	45.8
6–10 years	28	23.3
11–15 years	19	15.8
16–20 years	8	6.7
21 or more years	10	8.3
Sex		
Male (1)	3	2.5
Female (2)	117	97.5

^aSeven participants declined to provide demographic information.

RESULTS

One hundred and two emails were returned as undeliverable. Swoboda *et al.* (1997) demonstrated that 23% of undeliverable messages are not returned to the sender. Allowing for this, the number of undelivered messages was corrected to 132, leaving a sample of 633. A total of 128 subjects participated in the study; one ineligible respondent was excluded. Six respondents completed only the first section of the survey; they were excluded from the analysis of subsequent sections. After adjusting for the undelivered messages, the response rate was 20%. It is likely that many delivered messages were automatically filtered to bulk mail folders or deleted without notification (Sheehan, 2001); thus the actual response rate may be higher than the reported rate.

Demographic Characteristics

The demographic characteristics of the sample population are summarized in Table I. The mean years of service was 8.93 years. There was no significant difference in the years of service or gender distribution between this study population and that surveyed by the Professional Status Survey (PSS) (Parrott *et al.*, 2002). Summary data regarding self-perceived spirituality and religious affiliation are provided in Table II. Most respondents (81.7%) classified themselves as mildly, moderately, or strongly spiritual. There was a range of religious groups represented. For analysis, smaller groups were combined. Almost one-fourth of respondents reported no religious affiliation, comprising the largest single group.

Current Spiritual Assessment Practices

Of the 127 genetic counselors who responded to the survey, 76 (60%) indicated that they had performed a spiritual assessment in the past year. The reported frequency of sessions in which counselors performed spiritual assessment within the past year varied from 1–100% of sessions. Among those counselors who indicated they had performed spiritual assessment in the past year, the mean reported frequency was 20% of cases seen. Of those counselors who performed spiritual assessment, only 8.7% did so in more than half of their sessions. Counselors who performed spiritual assessment within the past year exhibited significantly higher perceived relevance and comfort with spiritual assessment ($p = .002$) compared to those who did not perform spiritual assessment. The primary reasons chosen for performing spiritual assessment were “the client brought up the topic of spirituality” (76.4%), “the session involved termination” (41.7%), and “the session involved end-of-life issues” (29.9%). Increased perceived relevance of spiritual assessment was associated with increased frequency of spiritual assessment ($p = .035$). Increasing comfort with performing spiritual assessment was not significantly associated with increased frequency of performing spiritual assessment ($p = .095$).

Table II. Spirituality and Religious Affiliation of Genetic Counselors.

	Total sample: $N = 120^a$	
	<i>n</i>	%
Self-perceived spirituality		
Not at all	11	9.2
Mildly spiritual	29	24.2
Moderately spiritual	37	30.8
Strongly spiritual	32	26.7
Very strongly spiritual	11	9.2
Religious Affiliation		
Jewish	14	11.7
Christian	12	10.0
Roman Catholic	22	18.3
Protestant ^b	25	20.8
Other ^c	9	7.5
None	29	24.2
Did not specify	9	7.5

^aSeven participants declined to provide demographic information.

^bBaptist, Episcopalian, Methodist, Presbyterian, Lutheran, Church of Christ.

^cUnitarian Universalist, Greek Orthodox, Hindu, Vedantin, Quaker, Buddhist.

A low perceived relevance (i.e., not at all or slightly important) of spiritual assessment to genetic counseling was indicated by 20.2% of respondents and low comfort (i.e., not at all or mildly comfortable) with spiritual assessment was indicated by 37.3%. Genetic counselors with a low perceived relevance were significantly more likely to also exhibit low comfort with the topic ($p < .001$). The identified barriers to spiritual assessment are listed in Table III. The predominant reason counselors identified for not assessing spirituality was lack of time in a genetic counseling session (45.7%). Another commonly cited barrier was perceived client discomfort (27.6%). Three barriers, not knowing how to assess spirituality (34% vs 7%; $p < .001$), not knowing what to do with the information gained (28% vs 7%; $p = .001$), and not being a religious/spiritual person (12% vs 3%; $p = .035$), were significantly more likely to be cited by counselors who had not performed an assessment than by those who had.

Neither years of practice, self-perceived spirituality, nor religious affiliation influenced counselors' spiritual assessment practices. There were too few males in the sample population to perform analysis by gender.

Feasibility and Appropriateness of HOPE tool

Comparison of the cumulative scores for perceived relevance and comfort showed significant variation among the four topics addressed by the HOPE tool (Figs. 1 and 2). The Friedman test provided a ranking of the four topics from most to least relevant and most to least comfortable; these rankings were statistically significant ($p < .001$). H questions were rated most relevant, followed by E, then O, and finally P; the ranking order for comfort was identical to that for relevance. H questions were ranked highest; 93.4% of respondents found at least three of the four questions relevant to genetic counseling and 53.7% indicated they would feel comfortable (score of 4 or 5) asking all of the questions. E questions were rated second in relevance and comfort; 86.0% found at least three of the four questions relevant and 27.3% indicated comfort with all questions. O questions were third; 49.6% of respondents found at least three questions relevant and 24.8% indicated comfort with all questions. P questions were ranked lowest in relevance and comfort; 31.4% of respondents found at least three of the four questions relevant and only 5.0% indicated comfort with all questions.

Table III. Barriers to Spiritual Assessment in Genetic Counseling.

	Total Sample: $N = 127^a$	
	<i>n</i>	%
Survey Supplied Barriers (Closed-ended)		
There is not enough time in the session	58	45.7
I think the client would be uncomfortable discussing spirituality	35	27.6
I do not know how to assess spirituality	22	17.3
I would not know what to do with the information	19	15.0
I do not think that the client's spirituality is important	14	11.0
I am uncomfortable discussing spirituality	9	7.1
I am not a religious/spiritual person	8	6.3
My own religious beliefs might conflict with those of the client	6	4.7
My spirituality might conflict with my client's	6	4.7
Spiritual assessment is the job of chaplains and clergy members	2	1.6
Respondent supplied barriers (Open-ended)		
Client did not bring up spirituality	19	14.9
Spirituality was not relevant to the session	16	12.6
I do not think assessment is necessary in basic GC sessions	10	7.9
Spirituality did not seem to be important to the client	8	6.3
The client resisted discussing the topic	2	1.6
Spiritual assessment is not my role	1	0.8
The physician I work with is uncomfortable with the topic	1	0.8
Spirituality is not assessed in follow-up sessions	1	0.8

^aRespondents were allowed to select more than one option.

After reading through the examples given from the HOPE spiritual assessment tool, 22.4% of respondents stated that they probably or definitely will begin incorporating spiritual assessment into their sessions using questions from the HOPE tool. An additional 46.7% of respondents indicated that they might incorporate spiritual assessment into their sessions using these questions. Counselors who had performed a spiritual assessment in the past year were ten times more likely to indicate they probably or definitely will incorporate the HOPE tool into their practice ($p < .001$). In addition, 65% of respondents felt that having a spiritual assessment tool would increase their ability to elicit relevant information from a client and 59.2% felt that having a spiritual assessment tool would increase their comfort in assessing client spirituality.

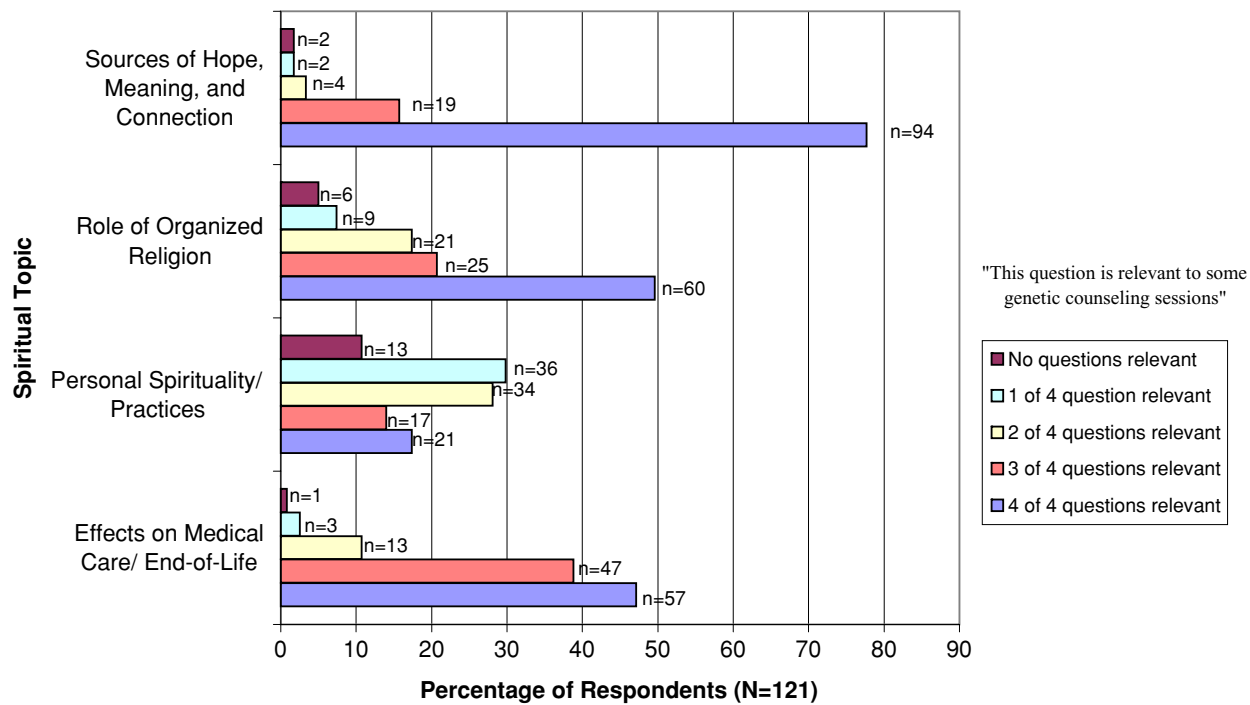


Fig. 1. Perceived relevance of spiritual topics to genetic counseling.

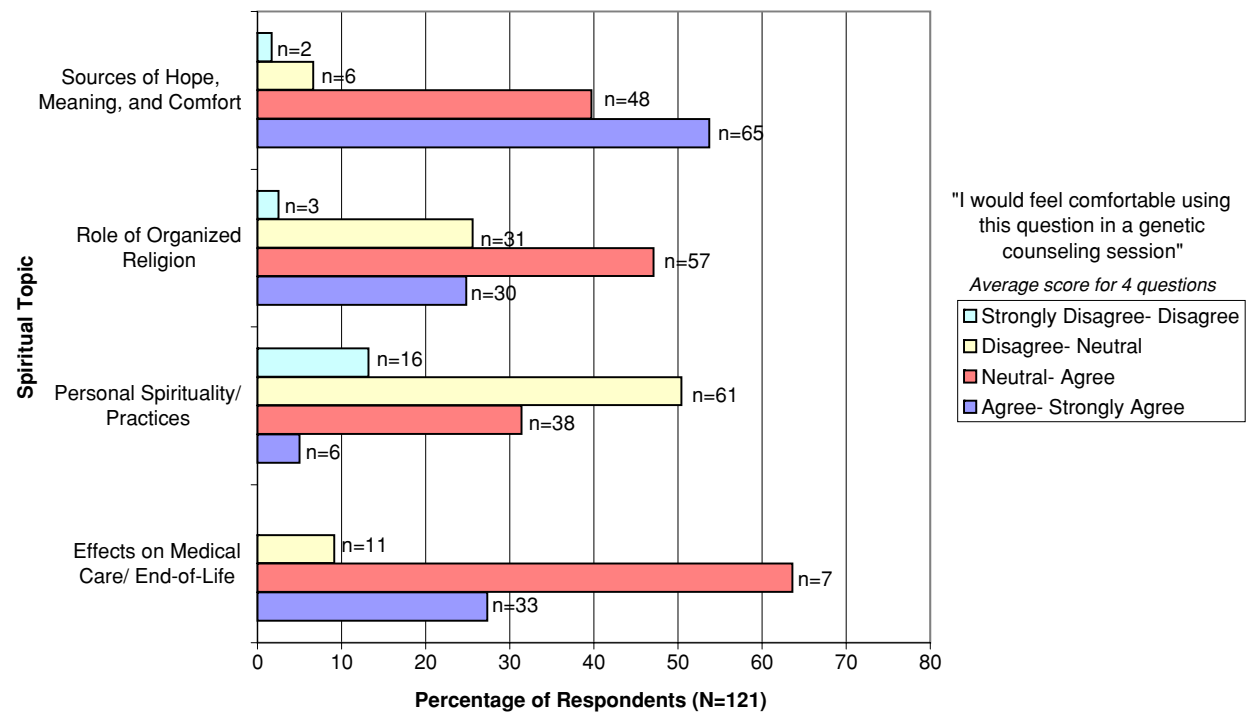


Fig. 2. Perceived comfort of genetic counselors in assessing spirituality.

DISCUSSION

The results of this exploratory study provide a snapshot of current spiritual assessment practices in genetic counseling. Although some spiritual assessment is occurring within genetic counseling sessions, it appears to be limited in nature. Even among counselors who reported performing spiritual assessment, only 8.7% did so for more than half of their sessions. There were too few respondents in this group to characterize those who perform frequent spiritual assessment. Assessment seems to occur in very specific situations. Many counselors indicated they had performed spiritual assessment when the client brought up the topic, when termination was discussed, or when end-of-life issues were involved. We surmise that in these situations counselors may be more comfortable assessing spirituality. If the client initiates the discussion, this resolves one of the major barriers to spiritual assessment (perceived client discomfort). Counselors may be more knowledgeable about the potential impact of religious beliefs when a client is faced with termination or end-of-life concerns and thus feel the topic is important to address in these situations. A recent publication by Rebecca Rae Anderson outlines the beliefs of major religious groups pertaining to prenatal genetic counseling (Anderson, 2002). Issues addressed include termination, pregnancy loss, and/or neonatal illness/death. Access to this resource has provided genetic counselors with a framework to understand the effect that a client's spirituality may have on his or her reaction when faced with termination or end-of-life concerns.

Perceived relevance of and comfort with spiritual assessment were directly related in this study. Genetic counselors seem to be more comfortable addressing spirituality if they can appreciate a direct application to the session. About one-third of counselors surveyed indicated minimal perceived relevance and comfort with spiritual assessment; these counselors were significantly less likely to have performed a spiritual assessment within the past year compared to those with a moderate to high perceived relevance and comfort. Perceived relevance was more significantly associated with the frequency of spiritual assessment than comfort, indicating that a genetic counselor's understanding of the importance of spiritual assessment may be a key factor in her decision to incorporate this assessment into practice. Discomfort with spiritual assessment may stem from a fear that just as psychosocial counseling follows from psychosocial assessment, spiritual

assessment will create a need for spiritual counseling. 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. In addition, counselors may feel uncomfortable with the unresolved dilemmas surrounding spiritual assessment in health care including the subjective nature of spirituality, the appropriate roles of members of the health care team in providing spiritual assessment and care, and uncertainty regarding the careful balancing of the needs for confidentiality and documentation of the information gained through spiritual assessment (McSherry and Ross, 2002).

Among counselors who had not performed spiritual assessment, 60% cited insufficient skills in spiritual assessment (e.g., not knowing how to assess spirituality or what to do with the information gained) as a barrier to spiritual assessment. Thus, education and training seem likely to significantly increase the number of counselors utilizing spiritual assessment within their practice. Lack of time was cited as a barrier both by those who had and those who hadn't performed spiritual assessment. While there is little that can be done directly to reduce this barrier, it seems likely that willingness to make time for spiritual assessment will increase as the perceived value of such assessment increases. Additionally, over one-fourth of participants anticipated that a client would be uncomfortable discussing spirituality; this belief contradicts studies showing that patients are interested in discussing their spirituality with health care providers (Ehman *et al.*, 1999; Kaldjian *et al.*, 1998; King and Bushwick, 1994). As genetic counselors, we routinely explore other sensitive topics with clients including drug and alcohol use during pregnancy, psychiatric illness, financial difficulties, and previous elective and/or spontaneous abortions. It is important to remember that "probing a client does not obligate her to share more than she is comfortable with..." (Biesecker, 2002, p. 263).

It is interesting to note that in this study, years of practice, self-perceived spirituality, and religious affiliation were not related to counselors' spiritual assessment practices. An earlier survey of genetic counselors corroborates the lack of relationship between personal spirituality/religion and clinical practices, noting that 66% of respondents felt their religious beliefs have minimal to no effect on their genetic counseling practice (Wyatt *et al.*, 1996). Yet, other studies of health care professionals dispute the lack of relationship between personal

spirituality/religion and clinical practices. One survey of genetic counselors found that respondents who were non-spiritual or non-religious had a lower level of comfort with the topics of spirituality and religion (Salamone, 2002). Similarly, studies from the nursing literature found that increasing personal spirituality was positively correlated with nurses' perceived ability and comfort in providing spiritual care (Taylor *et al.*, 1999). It may be that the non-directive ethos of genetic counseling has minimized the influence of counselors' personal spirituality on their spiritual assessment practices. As genetic counselors are specifically trained in non-directiveness due to the strong emphasis within the field on the importance of being non-directive and separating personal beliefs from practice in an attempt to avoid influencing client decision-making, genetic counselors' personal spirituality may be less apt to affect their spiritual assessment practices compared to other health care professionals.

Response to the introduction of the HOPE tool suggests that genetic counselors find certain spiritual topics more comfortable to discuss and relevant to genetic counseling. Overwhelmingly, counselors indicated highest perceived relevance and comfort with questions relating to sources of hope, meaning, and connection. This category includes topics that may already be incorporated into many counselors' psychosocial assessment. We also note that these questions address spirituality in a less direct manner. Questions dealing with effects on medical care/end-of-life issues were ranked second in perceived relevance and comfort. The application of religious beliefs to these topics is available to counselors within counseling resources with a psychosocial or multi-cultural counseling focus (Anderson, 2002; Fisher, 1996; Weil, 2000). The role of organized religion received a lower rating in both perceived relevance and comfort than the previously listed topics. In many settings, counselors may consider inquiry into a client's religious affiliation to be an intrusion into client privacy. Genetic counselors may address the role of organized religion due to the prevalence of certain genetic disorders within some religious groups, Tay-Sachs disease within the Ashkenazi Jewish population, for example. Alternatively, genetic counselors may inquire about ethnic background while taking a family history to avoid asking directly about religious affiliation. Questions related to the clients' personal spirituality and practices were consistently rated lowest in perceived relevance and comfort. This category of question

addresses spirituality most directly. Because of this, counselors may anticipate greater client discomfort with this topic and may be unsure of what they would do with the information, thus increasing the barriers to the assessment of this topic.

A previous survey of genetic counselors found that while 68% agree or strongly agree that spirituality/religion should be addressed with clients, over 70% of counselors rarely or never inquire about spirituality (Salamone, 2002). Introduction of a spiritual assessment tool alone may not be enough to substantially increase the frequency of spiritual assessment within genetic counseling. In our study, less than one-fourth of respondents indicated a high-likelihood of incorporating questions from the HOPE tool into their practice with greatest interest expressed by counselors who had performed a spiritual assessment. Even when presented with a model for spiritual assessment, genetic counselors that had not performed a spiritual assessment in the past year seemed reluctant to incorporate assessment into future sessions. Given that insufficient skills were cited as a primary barrier for non-performers, it seems likely that training in the utilization of the tool is needed; it was not our intention to model the proposed use of the tool within this survey. Based upon the comments we received, many participants interpreted the tool to be used as a complete list rather than selecting the questions which apply to a particular client. Additionally, because of the need to randomize the questions addressing each topic, the HOPE tool's gradual method of introducing spirituality was lost. Alternatively, the development of a tool unique to genetic counseling may be indicated.

Limitations

A primary limitation of this study was the low response rate. Because the invitation email came from a personal email account to multiple subjects, many invitations may have been filtered by recipients' accounts directly into a bulk mail or trash folder (Sheehan, 2001). A greater response may have been obtained through posting to the NSGC listserv or sending individual, personalized invitation emails. Additionally, a pre-notification email giving subjects the opportunity to opt out may have increased the response rate. While response rates to electronic survey methods vary, overall the response rate to email/Web surveys seems to be lower than that of paper surveys (Mertler, 2003; Sheehan and

McMillan, 1999; Solomon, 2001). In direct comparisons between traditional (paper) and Web versions of the same survey, Mertler (2003) and Matz (1999) found no significant difference in the responses of the two groups despite a 10% lower response rate in the groups completing the Web survey. Similar results were reported in several other studies (cited in Mertler, 2003).

Decreasing response rates have become a problem in many fields. Sheehan (2001) showed that response rates to electronic surveys have declined over the past 15 years. Mertler (2003) found that lack of time and difficulty accessing technology were the most frequent explanations chosen by non-respondents. A survey of general practitioners cited being “swamped” by questionnaires, little return on time spent completing, and receipt of invitation during a holiday period as the top reasons for non-participation (MacPherson and Bisset, 1995). It seems likely that these factors also influenced the response rate to this survey. Given the ABGC requirements for inclusion of a research component in all genetic counseling training programs, genetic counselors are likely receiving requests for participation in multiple studies during the late winter/early spring period. In addition, given that many thesis projects are not published, counselors may anticipate a low return on their investment of time in such projects.

Although the low response rate was likely influenced by the mode of questionnaire delivery, it is also very possible that the survey topic encouraged or discouraged the participation of some potential respondents. Previous studies have shown that salience, or perceived importance and/or timeliness, of the study topic is positively correlated to response rate (Heberlein and Baumgartner, 1978; Martin, 1994; Sheehan and McMillan, 1999; Sheehan, 2001; Thomas, 2004). Presumably, counselors who regularly perform spiritual assessment would perceive the topic as more salient, and thus be more likely to respond. If this is the case, these results may actually represent an over-estimate of the frequency of spiritual assessment.

Other limitations include lack of control for multiple responses from a single individual and limited piloting of the survey instrument, particularly in electronic form. The design of the introduction of the HOPE tool, with each HOPE question presented followed by two survey questions assessing response, created a need for a large amount of scrolling to complete this portion of the survey. This may have

created a perception of increased survey length and contributed to non-completion of the survey.

Our survey did not sufficiently characterize the demographic details of respondents versus non-respondents to determine the extent to which the study population appeared to be similar to genetic counselors as a whole. Thus, while this study provides an overview of the current attitudes and practices regarding spiritual assessment in genetic counseling, one must use caution in generalizing these results to the entire population of genetic counselors.

Future Directions

Further studies are needed to determine whether the results of this study provide an accurate representation of the perspective of genetic counselors as a whole. Given that the American population has expressed considerable interest in having their spirituality addressed by health care providers, more extensive characterization and quantification of counselors' perceptions and attitudes toward spiritual assessment is indicated. It is possible that spiritual assessment is occurring less formally within genetic counseling sessions as a component of psychosocial assessment. Restructuring the survey tool to inquire about how often a counselor addresses specific aspects of spirituality may yield different results. Another key aspect is identifying which spiritual assessment tool(s) may best fit the genetic counseling profession. This could be addressed through surveying which tools are currently being used by counselors and/or by providing information about a variety of tools and asking for feedback regarding each. If none of the existing tools seem to fit genetic counseling practice, this information could be used to guide the development of a tool unique to the profession. In addition, it will be important to determine whether the population of patients receiving genetic counseling differs from those with other health care needs. Exploration of patients' interests, needs, and attitudes toward discussing spirituality in the setting of genetic disease will help to define how the field should move forward in responding to this need.

Integration of spiritual assessment into the continuing education programs and clinical training for genetic counselors could be an important means of increasing the frequency of spiritual assessment within the field. Within this study, perceived relevance and comfort were significantly associated and

positively correlated to frequency of spiritual assessment. This suggests that increasing either counselor's perceived relevance or comfort will increase the frequency of spiritual assessment within genetic counseling. If counselors are trained regarding the reasons to inquire about client spirituality, they may feel more comfortable making such inquiries in clinic. Comfort may be further enhanced through demonstration of and training in techniques for spiritual assessment.

Boyle (2004) recommends that "clinical genetics professionals should develop a rudimentary understanding of issues associated with religious coping, including a capacity to assess patients' needs for pastoral counseling and determine how and to whom such patients should be referred" (Boyle, 2004, p. 8). As not every patient will have spiritual needs, nor will all such needs necessarily need to be addressed by the health care provider (McSherry and Ross, 2002), training must enable counselors to determine when additional spiritual care is needed. Incorporation of instruction in spiritual care into genetic counseling training programs represents an important means of improving the care provided to clients. Effective instruction must address both theoretical and practical aspects of spiritual care (Brush and Daly, 2000). Based on the models proposed for nursing education (Brush and Daly, 2000; Greenstreet, 1999; Lemmer, 2002; McEwen, 2004) and the American Counseling Association's spiritual competencies (Fukuyama and Sevig, 2002), teaching spiritual care in genetic counseling could include discussion of the meaning of spirituality and the role of genetic counselors in addressing spiritual concerns, a review of the beliefs of major world religions, instruction on aspects of religious coping, and presentation of spiritual assessment tools. The opportunity to practice spiritual assessment skills with peers and supervisors through participation in role-plays and clinical experience is critical to successful training (Brush and Daly, 2000). Examination of one's own spiritual beliefs, perspectives, and potential biases is another important component (Anandarajah and Hight, 2001, Fukuyama and Sevig, 2002). Where available, pastoral counselors, chaplains, and other clergy members could serve as guest lecturers to provide instruction and insight regarding spiritual assessment. Partnering with chaplains or a chaplaincy training program provides students with an opportunity to observe spiritual care-giving first-hand and create a network for future referrals. Similar interventions could be implemented at regional and/or

annual meetings for professionals already in the field.

While psychosocial assessment is well-established as a genetic counseling competency (I:4, II:2, III:1,2,4, Fine *et al.*, 1996; Weil, 2000), little attention is given to spiritual assessment. Although spiritual assessment is not directly named in the competencies, there is a focus on understanding clients' beliefs and values and conducting counseling in a culturally responsive manner (III:2, I:7, Fine *et al.*, 1996). As "spirituality and religious beliefs are embedded in culture" (Fukuyama and Sevig, 2002, p. 274), spiritual assessment is an important component of culturally sensitive care. The scope of psychosocial assessment may need to be expanded to include spiritual assessment. The standard assessment of coping and support systems provides a natural lead-in to inquiry regarding spiritual resources. Jon Weil notes "genetic counselors should be prepared to address issues of religion and spirituality with counselees. In many instances, the genetic counselor must open the discussion . . ." (Weil, 2000, pp. 51–52). Spiritual assessment within genetic counseling is a means of opening that discussion, allowing clients to share the ways in which their beliefs will influence their perception of genetic information.

APPENDIX 1: QUESTIONS FROM THE HOPE TOOL FOR SPIRITUAL ASSESSMENT AS PRESENTED IN THE SURVEY INSTRUMENT

H: Sources of hope, meaning, comfort, strength, peace, love, and connection:

- We have been discussing your support systems. I was wondering, what are your sources of hope, strength, comfort, and peace?
- What do you hold on to during difficult times?
- What sustains you and keeps you going?
- For some people, their religious or spiritual beliefs act as a source of comfort and strength in dealing with life's ups and downs; is this true for you?
- If the answer is yes, go on to O and P questions
- If the answer is no, consider asking: Was it ever? What changed?

O: Role of organized religion:

- Do you consider yourself part of an organized religion?
- How important is your participation in an organized religion in your life?

- What aspects of your religion are helpful and not so helpful to you at this difficult time?
- Are you part of a religious or spiritual community?
- How does being part of a religious or spiritual community help you?

P: Personal spirituality/practices:

- Do you have personal spiritual beliefs that are independent of organized religion? What are they?
- Do you believe in God?
- What kind of relationship do you have with God?
- What aspects of your spirituality or spiritual practices do you find most helpful to you personally? (eg, prayer, meditation, hiking)

E: Effects on medical care/end-of-life issues:

- How has this experience affected your relationship with God?
- Is there anything that I can do to help you access the spiritual resources that usually help you?
- Are you worried about any conflicts between your beliefs and your medical situation/care/decisions?
- Would it be helpful for you to speak to a clinical chaplain/community spiritual leader?

Adapted from: Anandarajah, G. & Hight, E. (2001). Spirituality and Medical Practice: Using the HOPE Questions as a Practical Tool for Spiritual Assessment. *American Family Physician*, 62(1), 81–89.

ACKNOWLEDGMENTS

We would like to thank the Bioethics Network of Ohio (BENO) for their generous grant which supported this research. We would also like to thank Gowri Anandarajah and Ellen Hight for granting permission to use the HOPE tool in our study

REFERENCES

- Anandarajah, G., & Hight, E. (2001). Spirituality and medical practice: Using the HOPE questions as a practical tool for spiritual assessment. *Am Fam Physician*, 62(1), 81–89.
- Anderson, R. R. (2002). *Religious Traditions and Prenatal Genetic Counseling*. University of Nebraska Medical Center: Munroe-Meyer Institute.
- Bash, A. (2004). Spirituality: the emperor's new clothes? *J Clin Nurs*, 13(1), 11–16.
- Biesecker, B. B. (2002, November). NSGC Practice Based Symposium- Spirituality in genetic counseling. *Strategies in Genetic Counseling: Beyond the Basics*, Symposium conducted at annual meeting of the National Society of Genetic Counselors, Phoenix, AZ.
- Boyle, P. J. (2004). Genetics and pastoral counseling. *Second Opin*, 11, 4–56.
- Brush, B. L., & Daly, P. R. (2000). Assessing spirituality in primary care practice: Is there time? *Clin Excell Nurse Pract*, 4(2), 67–71.
- Ehman, J., Ott, B., Short, T., Ciampa, R., & Hansen-Flaschen, J. (1999). Do patients want physicians to inquire about their spiritual or religious beliefs if they become gravely ill? *Arch Intern Med*, 159, 1803–1806.
- Fine, B. A., Baker, D. L., Fiddler, M. B., & ABGC Consensus Development Consortium. (1996). Practice-based competencies for accreditation of and training in graduate programs in genetic counseling. *J Genetic Couns*, 5(3), 113–121.
- Fisher, N. L. (Ed.). (1996). *Cultural and Ethnic Diversity: A Guide for Genetics Professionals*. Johns Hopkins University Press, Baltimore.
- Fukuyama, M. A., & Sevig, T. D. (2002). Spirituality in counseling across cultures. Pedersen, P. B., Draguns, J. G., Lonner, W. R., & Trimble, J. E. (Eds.), *Counseling Across Cultures*. (pp. 273–295). Sage Publications, Thousand Oaks.
- Gallup, G. H. (2002). *Religion in America*. Princeton Religion Research Center, New Jersey.
- Greenstreet, W. M. (1999). Teaching spirituality in nursing: A literature review. *Nurse Educ Today*, 19, 649–658.
- Greenwald, D. F., & Harder, D. W. (2003). The dimensions of spirituality. *Psychol Rep*, 92, 975–980.
- Hall, T. W., & Edwards, K. J. (2002). The Spiritual Assessment Inventory: A theistic model and measure for assessing spiritual development. *J Sci Study Religion*, 41(2), 341–357.
- Hatch, R. L., Burg, M. A., Naberhaus, D. S., & Hellmich, L. K. (1998). The Spiritual Involvement and Beliefs Scale: Development and testing of a new instrument. *J Fam Pract*, 46(6), 476–486.
- Heberlein, T. A., & Baumgartner, R. (1978). Factors affecting response rates to mailed questionnaires: A quantitative analysis of the published literature. *Am Sociol Rev*, 43(4), 447–462.
- Hodge, D. R. (2001). Spiritual Assessment: A review of major qualitative methods and a new framework for assessing spirituality. *Soc Work*, 46(3), 203–214.
- Kaldjian, L. C., Jekel, J. F., & Friedland, G. (1998). End-of-life decisions in HIV-positive patients: The role of spiritual beliefs. *AIDS*, 12(1), 103–107.
- King, D. E., & Bushwick, B. (1994). Beliefs and attitudes of hospital inpatients about faith healing and prayer. *J Fam Pract*, 39(4), 349–352.
- Koenig, H. (2002). *Spirituality in Patient Care: Why, How, When, and What*. Templeton Foundation Press, Philadelphia.
- Lemmer, C. (2002). Teaching the spiritual dimension of nursing care: A survey of U.S. baccalaureate nursing programs. *J Nurs Educ*, 41, 482–490.
- MacPherson, I. & Bisset, A. (1995). Not another questionnaire! Eliciting the views of general practitioners. *Fam Pract*, 12(3), 335–338.
- Martin, C. L. (1994). The impact of topic interest on mail survey response behavior. *J Market Res Soc*, 36(4), 327–338.
- Matz, C. M. (1999). Administration of Web versus paper surveys: Mode effects and response rates. Master's thesis, University of North Carolina. (ERIC Document Reproduction Service No. ED439694).
- Maugans, T. A. (1996). The SPIRITual history. *Arch Fam Med*, 5(1), 11–16.
- McEwen, M. (2004). Analysis of spirituality content in nursing textbooks. *J Nurs Educ*, 43(10), 20–30.

- McSherry, W., & Ross, L. (2002). Dilemmas of spiritual assessment: considerations for nursing practice. *J Adv Nurs*, 38(5), 479–488.
- McVay, M. R. (2002). Medicine and spirituality: A simple path to restore compassion in medicine. *S D J Med*, 55(11), 487–91.
- Mertler, C. A. (2003). Patterns of response and nonresponse from teachers to traditional and Web surveys. *Pract Assess Res Eval*, 8(22).
- Mills, P. J. (2002). Spirituality, religiousness, and health: From research to clinical practice. *Ann Behav Med*, 24(1), 1–2.
- Parrott, S., Clark, C., & Mahoney Shannon, K. (2002). National Society of Genetic Counselors: Professional Status Survey 2002. Boston Information Solutions.
- Puchalski, C. M., & Romer, A. L. (2000). Taking a spiritual history allows clinicians to understand patients more fully. *J Palliat Med*, 3, 129–137.
- Salamone, J. (2002, November). Spirituality and its inclusion in genetic counseling practice. *Strategies in Genetic Counseling: Beyond the Basics*, Symposium conducted at annual meeting of the National Society of Genetic Counselors, Phoenix, AZ.
- Schwartz, M. D., Hughes, C., Roth, J., Main, D., Peshkin, B. N., Isaacs, C., et al. (2000). Spiritual faith and genetic testing decisions among high-risk breast cancer probands. *Cancer Epidemiol Biomarkers Prev*, 9, 381–385.
- Sheehan, K. (2001). E-mail survey response rates: A review. *J Comput Mediated Commun*, 6(2).
- Sheehan, K. B., & McMillan, S. J. (1999). Response variation in E-Mail surveys: An exploration. *J Advert Res*, 39(4), 45–54.
- Solomon, D. (2001). Conducting Web-based surveys. *Pract Assess Res Eval* 7(19).
- Swoboda, S., Mühlberger, N., Weitkunat, R., & Schneeweiß, S. (1997). Internet surveys by direct mailing. *Soc Sci Comput Rev*, 15(3), 242–255.
- Taylor, E. J., Highfield, M. F., & Amenta, M. (1999). Predictors of oncology and hospice nurses' spiritual care perspectives and practices. *Appl Nurs Res*, 12(1), 30–37.
- Thomas, S. J. (2004). *Using web and paper questionnaires for data-based decision making : from design to interpretation of the results*. Thousand Oaks: Corwin Press.
- Thoresen, C. E., & Harris, A. (2002). Spirituality and health: What's the evidence and what's needed. *Ann Behav Med*, 24(1), 3–13.
- Treloar, L. L. (1999). Spiritual care: assessment and intervention. *J Christ Nurs*, 16(2), 15–18.
- Weil, J. (2000). *Psychosocial genetic counseling*. Oxford University Press, pp. 50–52.
- Wyatt, A., Best, R., Vincent, V., & Edwards, J. (1996, October). Religious convictions in genetic counseling: A survey of genetic counselors. *18th Annual Education Conference*, Symposium conducted at annual meeting of the National Society of Genetic Counselors, Oakland, California.
- Vandenbrink, R. A. (2001). Spiritual assessment: Comparing the tools. *J Christ Nurs*, 18(3), 24–27.