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ORIGINAL RESEARCH

"Be Prepared if I Bring It Up:" Patients' Perceptions of the Utility of Religious and Spiritual Discussion During Genetic Counseling

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Abstract As debates continue about the relevance of religion to health care, research is needed to guide decisions about whether genetic counselors (GCs) should routinely address religious and/or spiritual (R/S) issues with their patients. We conducted an online survey to gauge patient perspectives on this issue. Among the 70 respondents, frequencies of closed-ended responses and thematic analyses of open-ended responses revealed multiple patient concerns related to R/S discussions with GCs. Although 60 respondents reported being R/S, only a small minority would want to discuss R/S issues if it meant less time discussing medical information. Most respondents also expressed opinions that: 1) genetic counseling should be about science; 2) GCs are not qualified to discuss R/S issues; 3) other outlets are available to meet the needs of patients who want R/S counseling; and/or 4) R/S discussions are more likely to be acceptable if patients broach the topic or in specific circumstances (e.g., when patients are facing end-of life issues). Overall, responses suggest routine or comprehensive R/S assessments or discussions are not necessary and that GCs would be best equipped to help all their patients if they were prepared to listen, be supportive, and make referrals when R/S issues arise in clinic.

Keywords Genetic counseling content · Religion and spirituality · Religion and health · Patient perspectives · Qualitative research

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Introduction

In recent years, healthcare institutions and professions have shifted toward a more holistic provision of services wherein cultural competency and patient values are central to understanding and working with patients to achieve optimal health outcomes (Puchalski et al. 2014). Considering the majority of Americans report being at least moderately religious (Newport 2012), religion represents one of the primary cultural elements medical practitioners have considered incorporating into healthcare service delivery. In fact, such consideration can be seen in recent suggestions by the Joint Commission for Accreditation, Health Care, and Certification requiring spiritual assessment as a component of care, treatment, and services in hospitals (The Joint Commission 2010). It is also observed in the important debate regarding whether genetic counselors (GCs) should routinely incorporate religious and/or spiritual (R/S) assessment or discussion into their practice (Cragun et al. 2009; Reis et al. 2007; White 2009).

To this end, some researchers began to explore potential relationships between religion and genetic counseling. For example, Anderson (2009) found that religious doctrine often relates to issues in prenatal genetic counseling, and thus may have effects on the ways patients approach decision-making in prenatal settings. Reis and associates (2007) surveyed GCs to determine if they were incorporating R/S assessment into their counseling and found 60 % of their respondents performed

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spiritual assessments within the past year, but only 8.7 % of these did so in more than half of their cases. Further, 80 % of GCs surveyed believed religion was relevant, but also revealed they would be more likely to engage this topic if patients approached it first.

Despite the potential relevance of R/S assessment and discussion to genetic counseling, it appears no studies have been published in peer-reviewed journals investigating patient preferences regarding the possibility of GCs broaching topics related to their patients' religion and/or spirituality. Such data would be important as it could inform what should be included in a cultural competency model for GCs. If, for example, respondents demonstrate a desire for R/S assessment and discussion as part of genetic counseling, then it could be beneficial for GCs to receive more training in these issues, including how best to broach this topic. Conversely, respondents may not desire for GCs to initiate R/S discussions or prefer them to focus on other issues. Understanding patient perspectives will inform genetic counseling practice and training to facilitate cultural competency. To this end, we explored patient responses regarding the possibility of R/S discussions with GCs in hopes of providing recommendations for optimal and culturally competent patient care.

Methods

Study Population and Recruitment

The population we approached to complete an anonymous online survey consisted of a convenience sample contacted through the Genetic Alliance's Community Forum Listserv. The Genetic Alliance is a nonprofit health advocacy organization with a network of over 1200 organizations (www.geneticalliance.org). Their members represent a broad array of genetic conditions and experiences. Listserv members (approximately 500) were invited to participate in the study and share the study link with others within their networks and organizations. To be included in the study, respondents had to be 18 years of age or older and indicate they participated in genetic counseling for themselves, a family member, or a friend. Before initiating the study, the Wayne State University Institutional Review Board Committee designated these research procedures and data collection efforts exempt.

Survey Instrument

The study instrument is a shortened, modified version of a 112-item instrument developed by MacLean and associates (2003) to assess patients' preferences with regard to religion and/or spirituality in general medical contexts. Several baseline information questions in the MacLean survey were replaced with questions applicable to genetic counseling. For example, Likert scale questions in the original survey which focused on hospitalization and prayer were replaced with open-ended questions. Specifically, all respondents were asked how they would feel if a GC "addressed spiritual and/or religious issues" during their genetic counseling session. In addition, those who answered "yes," when asked if they were at least somewhat R/S, were given additional questions. These included why they would or would not want a GC to address R/S needs or concerns related to their genetic issues and under what circumstances they would or would not want a GC to discuss religion and/or spirituality with them.

The final survey contained 27 questions broken into the following sections: eligibility and informed consent (2 questions), background information (indication for genetic counseling, R/S discussion during genetic counseling; 8 questions), R/S beliefs and opinions (9 questions), and demographics (8 questions). No identifying information was requested. The eligibility section included the study information sheet and a question about whether the potential respondent had participated in a genetic counseling session, defined as meeting with "someone who helps people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease" (Resta et al., 2006). Those who consented to participate and indicated they participated in genetic counseling were considered eligible to complete the study survey.

Data Analysis

Frequencies were calculated to characterize respondents' demographic profiles and responses to closed-ended questions about religion and/or spirituality. Seeking to gain a more in-depth and nuanced understanding of patients' attitudes concerning the potential incorporation of R/S discussion into genetic counseling, a grounded approach was utilized (Grubs and Piantanida 2010), and we explored all the text in open-ended questions to identify themes in the responses. In so doing, we sorted the statements into categories, and then compared and contrasted responses in the categories until we reached common elements of each. We refined our categorical labels to capture the themes in respondents' responses. At the completion of this iterative process (Corbin and Strauss 2008), we arrived at the findings presented below.

Once the themes from responses were identified, one author reviewed all open-ended responses for each respondent and categorized each respondent into three categories according to the following: 1) all of the respondents' open-ended responses were consistently in favor of R/S issues being raised; 2) the respondents' responses were mixed; or 3) the respondents' responses all consistently argued against having GCs raise or discuss R/S issues unless the issues are raised by the patient. Once categorization was completed, another

author independently verified the classifications. One discrepant case was subsequently discussed and re-classified after consensus was reached among the two authors.

Results

Of the 86 individuals who agreed to participate and were eligible for the study, 16 were excluded from the analysis because they answered fewer than 10 questions and none of the open-ended questions. The final sample consists of 70 respondents; 60 responded yes when asked whether they consider themselves at least somewhat R/S. Table 1 characterizes respondents in terms of demographic, religious, and genetic counseling session variables for the entire sample and according to whether they reported being at least somewhat R/S. The vast majority of respondents were female (86.8 %), married, (82.4 %) White (92.6 %), Non-Hispanic (89.6 %), and designated a religious affiliation (74.6 %). Respondents most commonly reported participating in a genetic counseling session as either the patient (36.2 %) or the parent of the patient (50.7 %). Respondents were distributed across all specialties with the largest proportion participating in pediatric genetic counseling (31.4 %). Some specific reasons for genetic counseling observed in more than one open-ended response included cleft lip and palate, Barth syndrome, BRCA, Loeys-Dietz syndrome, fibromuscular dysplasia, and MCAD deficiency.

The majority (57 %) of all respondents answered "yes" when asked if GCs should be trained in addressing R/S beliefs. Among the 60 respondents who indicated they were R/S to any degree, only 18 % had discussed R/S issues with their GC. Two R/S individuals reported the GC first broached the topic and 10 reported they or a family member first broached the topic. Only two respondents reported seeing a GC who self-disclosed his/her own R/S beliefs.

Closed-ended questions, asked only of the 60 respondents who reported being at least somewhat R/S, revealed 42 % would want their GC to discuss R/S issues related to their genetic risk or condition. However, when asked whether they would want to discuss religion and/or spirituality if it meant spending less time discussing medical or risk information, only 18.6 % responded "yes." Widely varying opinions were found among the 60 R/S respondents with regard to several additional questions rated on an 11-point scale (Figs. 1–4). Specifically, when asked if they would want their GC to "be aware of" their R/S beliefs, 22 % indicated "not at all" (rating of 0), 29 % indicated "maybe" (rating of 5), 22 % indicated "definitely" (rating of 10), and the remainder were fairly evenly distributed between the end-points (Fig. 1). A similar tri-modal trend was observed regarding the question of whether they want their GC to "ask about" their religion and/or spirituality (Fig. 2). Over 70 % of R/S respondents indicated they would understand if their GC did *not* want to have R/S discussions as evidenced by a rating of 6 or above (Fig. 3). Furthermore, 57.4 % believed that GCs are only somewhat qualified or not at all qualified to address patients' R/S issues with them as evidenced by a rating of 4 or lower (Fig. 4).

Only 3 out of the 70 total respondents did not answer any open-ended questions related to addressing R/S issues in genetic counseling. These 3 respondents considered themselves to be at least somewhat R/S and, based on closed-ended questions, they were neutral about wanting their GC to address R/S issues with them. Among the remaining 67 who responded to open-ended questions, thematic analysis of all response identified three main patterns of reactions, including: 1) a subset of responses reflecting a desire for GCs to address R/S issues; 2) a subset of responses which did not want GCs to address R/S issues; and 3) a subset of responses which expressed ambivalence or favored R/S discussions only under certain conditions. These patterns are reflective of the tri-modal responses to the closed-ended questions, but they also include responses from the 10 non-religious and non-spiritual or unsure individuals. Themes that emerged within each of these three main patterns are illustrated in the following sections.

GCs Should Address Religious and/or Spiritual Issues

A subset of our responses reflected the belief that GCs should address R/S issues, or minimally be prepared to discuss them. However, rather than suggesting the incorporation of R/S issues should be absolute or uniform, some respondents in this group suggested religion and/or spirituality represented an element that "could" be important to genetic counseling. In so doing, they stopped short of saying R/S discussion *must* be part of genetic counseling but suggested specific ways it should be approached, addressed, or considered by GCs in relation to patient needs.

The two most common themes which emerged from respondents who suggested GCs should incorporate R/S issues to some extent involved preparation and tolerance. As reflected in our title, some respondents suggested GCs should be prepared to handle R/S issues if they came up in counseling sessions, as the next two illustrations reveal:

> I would rather a counselor only address religion or spirituality if I were the one who brought it up first (21 year old, single, White, Atheist, female).
>
> I do believe that spiritual and religious beliefs play a role in the decision making process for those who that is important, so they should be prepared to encounter concerns and issues in this area (33 year old, married, White, Anglican, female).

Rather than calling for incorporation of R/S discussion into genetic counseling in any systematic way, such respondents

Table 1 Frequencies for demographic, religious, and genetic counseling experience variables among all respondents and according to their religious and/or spiritual (R/S) degree

Variable	All respondents ($N = 70$)		Respondents indicating a R/S degree ($n = 60$)		Respondents indicating *no* R/S degree or unsure ($n = 10$)	
Age (years)						
Mean	43.4		44.5		37.6	
Median	43		44		38.5	
Range	18–64		18–64		18–51	
	N	%	N	%	N	%
Sex						
Male	9	13.2	8	13.8	1	10
Female	59	86.8	50	86.2	9	90
Marital status						
Married	56	82.4	48	82.8	8	80
Single/never married	7	10.3	5	8.6	2	20
Divorced/separated	3	4.4	3	5.2	0	0
Widowed	2	2.9	2	3.4	0	0
Race						
White	63	92.6	54	93.1	9	90
Other	5	7.4	4	6.9	1	10
Hispanic						
Hispanic	7	10.4	5	8.8	2	20
Non-Hispanic	60	89.6	52	91.2	8	80
Educational attainment						
High school or GED	2	2.9	2	3.4	0	0
Some college	17	25	15	25.9	2	20
Four year college degree	23	33.8	21	36.2	2	20
Graduate or professional degree	26	38.2	20	34.5	6	60
Religious affiliation						
Catholic	17	25.4	16	26.7	1	10.0
No religious affiliation	11	16.4	9	15.0	2	20.0
Protestant	9	13.4	9	15.0	0	0.0
Mormon	6	9.0	6	10.0	0	0.0
Atheist	5	7.5	0	0.0	5	50.0
Jewish	4	6.0	3	5.0	1	10.0
Baptist	2	3.0	2	3.3	0	0.0
Hindu	2	3.0	2	3.3	0	0.0
Agnostic	1	1.5	1	1.7	0	0.0
Greek Orthodox	1	1.5	0	0.0	1	10.0
Other (specified)						
Unitarian	1	1.5	1	1.7	0	0.0
Science of mind	1	1.5	1	1.7	0	0.0
Sikh	1	1.5	1	1.7	0	0.0
Bahai	1	1.5	1	1.7	0	0.0
Anglican	1	1.5	1	1.7	0	0.0
Christian	2	3.0	2	3.3	0	0.0
Church of England Christian	1	1.5	1	1.7	0	0.0
Pagan/Wiccan	1	1.5	1	1.7	0	0.0
Religious attendance in last 12 months						
Never	16	23.5	10	17.2	6	60

Table 1 (continued)

Variable	All respondents ($N = 70$)		Respondents indicating a R/S degree ($n = 60$)		Respondents indicating *no* R/S degree or unsure ($n = 10$)	
1-11 times	18	26.5	14	24.1	4	40
Once a month	5	7.4	5	8.6	0	0
Once a week	24	35.3	24	41.4	0	0
More than once a week	5	7.4	5	8.6	0	0
Role in most recent counseling session						
Patient	25	36.2	22	37.3	3	30
Spouse or significant other	1	1.4	1	1.7	0	0
Parent of patient	35	50.7	29	49.2	6	60
Mixed roles or other	8	11.6	7	11.9	1	10
Type of counseling received						
Pre-conception	3	4.3	3	5	0	0
Prenatal	9	12.9	8	13.3	1	10
Cancer	8	11.4	8	13.3	0	0
Pediatric	22	31.4	18	30	4	40
Adult (non-cancer)	9	12.9	7	11.7	2	20
Other or multiple	19	27.2	16	26.7	3	30
Years since last counseling session						
Mean	6.52		6.83		4.44	
Median	3		3.5		3	
Range	0–29		0–29		0–13	

wanted counselors to be "prepared" for this possibility especially in "worst case scenarios." A couple of respondents took this a step further by suggesting counselors should ask patients about R/S issues as illustrated in the following response:

> I think it is important for them to get in the habit of asking patients. Even if their only answer to the patient's concern is 'discuss w/your spiritual advisor' or even if the patient has no concerns, simply asking the patient about any religious concerns shows the counselor is taking in to account that the patient is a whole person and not just a disease (29 year old, married, White, no religious affiliation, female).

This type of reasoning suggests asking about R/S issues could be used to show holistic concern for the person.

The second common theme in the responses favoring R/S incorporation involved demonstrating tolerance for religion. These types of suggestions echo some concerns which also arose among several respondents in the group of respondents who explicitly did not want R/S discussions incorporated into genetic counseling and in the group who only wanted it incorporated in certain contexts. As the following illustration suggests, the heart of this type of response involved concerns regarding how GCs might react to one's R/S beliefs and practices in relation to medical care:

> I want the person that wants no treatment due to belief to be understood. My family is Christian and we believe life is when egg meets sperm. We believe in right to life, no matter what disability we accept. I didn't like the abortion information at 22 weeks with genetic counselor if she used my belief in god it would have been a how to care for my child instead of delete the child (54 year old, married, White, Christian, female).

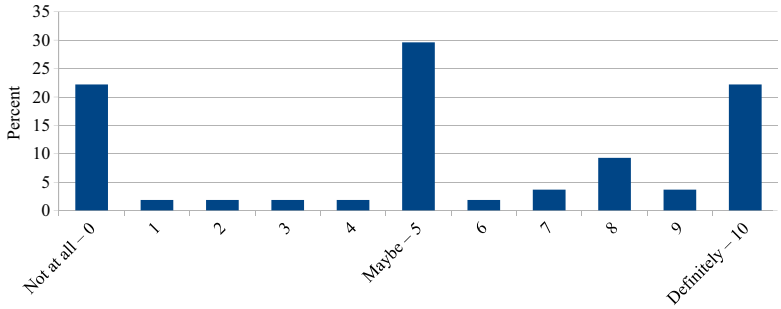
As the examples above illustrate, a handful of respondents thought incorporating R/S discussions might be useful if it was done in a way that created more tolerance for *their* beliefs about the nature of life. Interestingly, the only four examples of this type of response involve abortion and medical decisions about pregnancy, which suggests this type of reaction might be limited to the context of reproductive medical interventions.

Unlike those who expressed concern about receiving medical advice which would contradict their R/S beliefs, the following quote is from a lone respondent who seemed to welcome alternative perspectives:

> Our religious/spiritual beliefs (even when they are not very strong or rigid) helps shape and impacts important decisions that we make for ourselves and on behalf of our children. When we are in the middle of a situation it

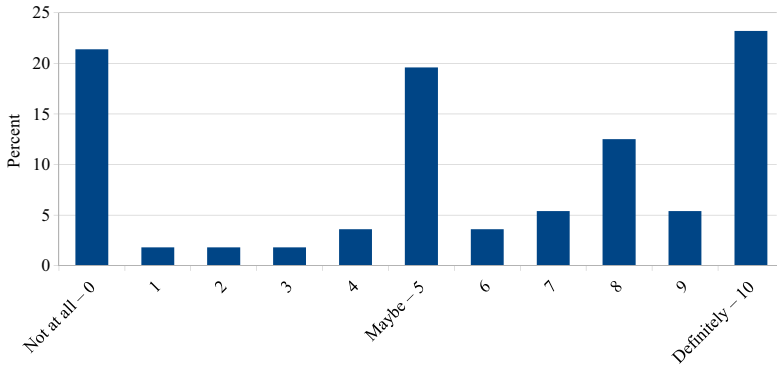
1

In general, would you want your genetic counselor to be aware of your religious and/or spiritual beliefs?



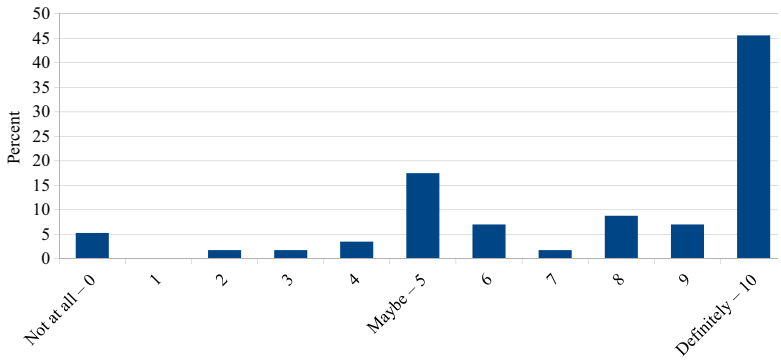
2

Would you want your genetic counselor to ask you about your religious and/or spiritual beliefs?



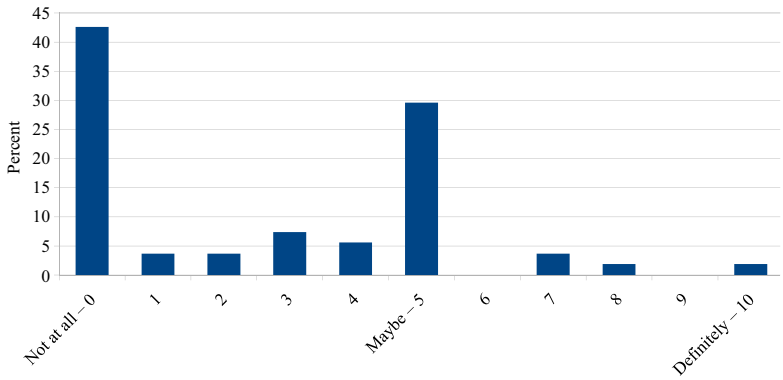
3

Would you understand if your genetic counselor did not want to discuss religious and/or spiritual beliefs with you?



4

Do you believe your genetic counselor is qualified to address your religious and/or spiritual matters with you?



Figs. 1–4 Respondents' perspectives on the role of religion and/or spirituality in genetic counseling sessions. Due to a skip pattern in the survey, only those 60 respondents who indicated being at least somewhat religious or spiritual were asked these questions. Valid percentages are reported because 3 to 6 respondents either selected "no preference" or left the question unanswered

> is sometimes hard for us to separate ourselves emotionally and make sound decisions. Having a caring and compassionate counselor who can help us see things from various points of view, walk us and talk us through things can help us make better decisions. It can help resolve our emotional conflicts and help us cope better with the disease and it's implications (50 year old, married, Asian, Hindu, female).

GCs Should Not Address Religious and/or Spiritual Issues

Many open-ended responses suggested that GCs should not address R/S issues. They argued religion and/or spirituality is not "relevant" to genetic counseling, and caution against bringing up such controversial subjects. Even so, these responses revealed nuances within this stance where some of them agreed religion and/or spirituality might be important to some people in some cases and have use in some patients' lives and decision-making processes, but they argued R/S discussion had no necessary place in genetic counseling.

The three main themes which emerged from responses which were unfavorable to having GCs address religion and/or spirituality involved training, professionalism, and acceptance. In the first case, many respondents, as the following examples note, argued GCs are not trained to provide R/S guidance or information:

> I feel that the GC is not my religious leader and does not need to discuss the religious issues with the situation. The biggest thing for me is to be respectful of my religion and decisions (29 year old, widowed, White, Mormon, female).
>
> She/he is not a trained religious advisor or even a member of a patient's religion. He/She has a scientific background and is fact based/science based person that should only report facts and present options (37 year old, married, White, Catholic, female).
>
> Religion and spirituality are very personal and unique to each individual. A GC is not a spiritual leader or student of religion. They should stick to the facts as they are known (66 year old, married, White, Catholic, female).

Rather than incorporating religion and/or spirituality into genetic counseling, many of our respondents, as the previous and next illustrations reveal, argued GCs should stick to the scientific work they were trained to do and leave R/S concerns to those with R/S training:

> To be honest, your average GC has no training in religion beyond general knowledge of religion, or experience from within their own religion. As in a hospice situation, talking about beliefs would be helpful to some who do not have a background in religion, but there are such a wide and diverse number of religions, that it seems ridiculous to expect a GC to be of much help discussing Christian principles, with, say, a Buddhist, for example. We have freedom of religion in the USA, so one could ask a patient whether they'd like to discuss religion, but to be honest—it might be best if they were referred to a counselor of their particular religion (46 year old, married, White, Mormon, female).

Importantly, these respondents considered things noted by those who were favorable towards R/S discussions (i.e., tolerance and preparation) but argued these issues provide reasons GCs should not have R/S discussions with patients. In fact, the general consensus in the majority of open-ended responses in our data appears to suggest it would be "ridiculous" for someone without R/S training to broach R/S topics with patients who come to them for the genetic "facts as they are known."

The second most common theme among responses arguing GCs should not address R/S issues concern professional boundaries. Drawing on notions of training in the earlier examples, these respondents interpret GCs as medical professionals, and thus would see the incorporation of religion and/or spirituality into genetic counseling as a breach of boundaries between science and religion. As the following illustration reveals, many respondents did not like the idea of discussing R/S issues with medical experts:

> I very specifically do not want any medical professional discussing religion with me in any context. Medical professionals are administering scientific-based care. I would however support a GC having resources to refer patients to a faith-based counselor with awareness of genetic issues and see a great opportunity for hospital chaplains to fulfill this role. I do understand how people with certain beliefs could greatly be challenged by genetic findings that would permanently impact their child's life and their lives as parents. However for any conversation to be of true help to a family, that family must be made keenly aware of all scientific truths (33 year old, married, White, no religious affiliation, female).

Such responses, especially common in our dataset, revealed that respondents believe GCs have a responsibility to educate patients on scientific findings. Some respondents were further concerned that R/S discussions are both personal and separate from the science of genetics, as the next quote suggests:

> Religion and spirituality are an individual process. Mine is mine and yours is yours. I don't want someone I do not know on a personal level injecting his or her religious beliefs into my circumstances. Genetics is science whereas religion and spirituality are beliefs. If I had

> religious and spiritual concerns, I would turn to a trusted advisor. No two religions are the same. No GC could have knowledge enough to encompass the spectrum of beliefs (37 year old, married, White, Agnostic, female).

As another respondent put it, several who participated in our survey wanted GCs to provide "the cold hard facts" so they could make decisions for themselves. In fact, some of these respondents explicitly interpreted R/S incorporation into genetic counseling to be a potential overreach:

> It seems that this would be more the role of a counselor/psychologist or spiritual advisor. Genetic counseling, as I understand, is very medical and not "touchy feely" it seems like it would be out of the purview of the GCs abilities? I just would like the GC to be able to tolerate/listen to spiritual thoughts about the situation and acknowledge these concerns and perhaps suggest a more qualified professional (52 year old, married, White, Hindu, female).

This group of respondents argued GCs were not the type of professionals they thought should be discussing R/S issues. Rather, they suggested GCs should provide insights from their scientific profession, and that patients could seek R/S professionals for non-scientific needs.

The third primary theme which emerged among respondents who did not want GCs to address religion and/or spirituality involved concerns about acceptance. Similar to the themes concerning tolerance noted in the previous section, these respondents were concerned GCs might push their own religion and/or spirituality on patients and saw this as a dangerous possibility. Rather than believing R/S incorporation might aid tolerance or acceptance, however, they suggested leaving R/S discussion out of genetic counseling as the better approach to managing patients from varied R/S backgrounds. In so doing, they argued, as evidenced in the next four illustrations, GCs should strive to be impartial and simply listen to and be supportive of the patient's perspective:

> Everyone has individual beliefs, even within the same religions. I would not like anyone trying to influence my families decisions based on their idea of religion.
>
> I think whatever the patient's values are they need to be supported in their beliefs. I feel that a GC must be impartial, supportive, and sensitive to the patients' needs and above all unbiased (43 year old, married, White, no religious affiliation, female).
>
> Beliefs are just that, one's own belief structure. Not many people can relate to one's spirituality unless it's in a conventional form of religion. I think more definition between religion and spirituality is needed (31 year old, single, White, Pagan/Wiccan, male).
>
> I think the GC should listen to my perspective—my religious conviction affects my worldview & my decision maker. Counselor shouldn't become a spiritual guide, but should listen & reflect back, and take my perspective seriously (61 year old, married, White, Protestant, female).

Alongside notions of impartial acceptance of patients' religion and/or spirituality, other respondents, as noted in the next illustration, expressed concern about GCs pushing their own R/S views on patients in the course of their work:

> This is not the place of the GC. I expect a GC to be respectful of my religion/spirituality and not push when I make choices based on my personal belief system. I do not want a GC to in any way impinge on my freedom of religion and I do not care to impinge on theirs. Mutual respect and a professional and knowledgeable appointment is all I want or require (48 year old, married, White, Protestant, female).

Rather than incorporating religion and/or spirituality, these respondents echoed earlier notions of preparedness on the part of counselors that stopped short of engaging R/S discussion itself:

> I would want the GC to be aware of the repercussions that religion might have on certain decisions and would want to hear about them. But I wouldn't want to be asked about my religion/spirituality because there is no way a geneticist would understand the nuances and permutations of choices made by a person (67 year old, married, White, undisclosed religion, female).

Put simply, many of these respondents suggested there was a line GCs should attempt not to cross. From their perspectives, illustrated by the responses below, engaging in R/S discussion would cross this line and they would be offended if it went beyond demonstrating an awareness and acceptance that some people are R/S:

> I most likely would be offended if the counselor went beyond asking, "Are there any religious or spiritual concerns you would like to address in light of these genetic findings?" The GC should never insert his or her own beliefs into any interaction with patients (33 year old, married, White, no religious affiliation, female).
>
> I would hate it, it's offensive and presumptuous of them to push religion. They are doctors and we are there to talk about medicine and science (33 year old, married, White, Atheist, female).

GCs Should Be Cautious When Addressing or Not Addressing Religious and/or Spiritual Issues

As implied in many of the previous examples, respondents' opinions suggest GCs should be careful about decisions regarding the incorporation of religion and/or spirituality in counseling sessions. Despite advocating for opposing sides, responses from the first two groups suggest that incorporating religion and/or spirituality might represent a very dangerous topic for GCs to address. In fact, when we look at the third group of respondents, who did not explicitly argue for or against R/S incorporation, we found two themes which may aid decision-making about whether or not GCs should incorporate R/S issues.

The first theme, which emerged from respondents who appeared to be more ambivalent or undecided about R/S incorporation, involved respect for diversity. As hinted in the other two groups and explicitly noted in the next three illustrations, respondents thought religion and/or spirituality should be approached with caution, sensitivity, and respect since many different R/S beliefs and practices operate in concert with one another in our world today:

> I would want the GC to be sensitive to my wishes to discuss or refrain from discussing these issues, and the degree or depth of the discussion (59 year old, married, White, Catholic, male).
> I would want the counselor to respect my religious beliefs and not belittle them (39 year old, married, White, Catholic, female).
> It would depend on the approach they took. If they were pushing ideas on me, then the answer would be no. If they were just asking in order to support me the way I needed, and seeking to understand my beliefs in order to do this, then yes (30 year old, widowed, White, Protestant, female).

These respondents emphasized understanding on the part of GCs, and, as noted in the next illustration, suggested that awareness, respect, and possibly referrals by the GCs might be the most important or useful approaches for the widest variety of patients and situations:

> I think it would be important for a GC to appreciate spiritual dynamics of the decision makers (patients, parents, guardians). A diagnosis of a heritable genetic disease in one's family can lead to tremendous conflict when making critical decisions. If nothing else the GC needs to be aware of these issues to make further suggested referrals to the family (53 year old, married, White, no religious affiliation, female).

This preference for preparation and referral rather than incorporation becomes even clearer in relation to the second primary theme which emerged from more ambivalent respondents. In such cases, respondents created an "if / then" test for incorporating religion and/or spirituality into genetic counseling. Wherein, "if" certain factors were present "then" it would be good, but "if" other factors were present, "then" it would be a bad idea to bring up religion and/or spirituality. As the following examples reveal, these "if / then tests" basically leave GCs who incorporate religion and/or spirituality into their work in a "no win" situation wherein any approach they take may lead to negative experiences and outcomes as often as it may lead to positive experiences and outcomes:

> It would depend on their faith. I don't think an agnostic or atheist would be qualified to help me spiritually. But if they were of same faith then it would be fine.
> I would like it only if I knew that the GC had the same beliefs or shared the same "religion" (41 year old, married, White, Baptist, female).
> It might be difficult for a GC to address those issues depending on their own faith base. They might only understand concerns if they shared the same faith or spiritual preferences (44 year old, divorced/separated, White, Catholic, female).
> It would depend on their views—if they were an atheist then I would definitely NOT want to know that fact. I think I would rather have someone with my similar beliefs or not be able to tell what their views were (44 year old, married, White, Catholic, female).
> If I spoke up and said I won't do an amino because I will keep the child no matter what or that I would not abort a child with a known defect I would be grateful if a doctor who shared my belief showed solidarity in my decision. If the doctor disagreed with my decision, I would expect that doctor to keep his opinion to himself (48 year old, married, White, Protestant, female).

It is important to note the only way to avoid all of the possible negative outcomes created by these "if / then" interpretations is to ensure that GCs not disclose their own R/S beliefs or lack thereof. In fact, as the next illustration reveals, respondents themselves noticed the potential dynamics that could play out if counselors self-disclosed their own R/S beliefs and suggested the provision of resources or referrals to other individuals (e.g., chaplains, clergy, spiritual counselors, etc.) might be the best possible approach for GCs.

> It really depends if we have the same beliefs. If they believed the same as we did and we were struggling with something, it would be great to receive their wisdom in that situation. If they believed differently, I could see how it could be a hindrance to all involved by conflicting viewpoints and attitudes. I think it would be

> difficult for the counselor to give advice with their whole heart if they don't personally believe what they are giving advice on. I think there's a difference in being quiet/respectful about seeing/listening to a patient's beliefs and helping them in whatever way they need help, than hearing the patient's story and verbally and physically judging them for their choices. No one wants to be judged. It would be nice for the GC to explain things simply from a medical standpoint, leaving all judgment aside, and have available resources ready if the patient is wanting additional guidance regarding religious and spiritual matters (34 year old, married, White, Christian, female).

The thematic analysis revealed several nuances in responses and a single person often expressed a combination of these different themes in open-ended responses to different questions. To capture overall sentiments of each respondent based on all of their open-ended responses, we grouped respondents into three main groups. One respondent was not included who maintained neutrality and indicated genetic counseling was a "waste of time" in open ended responses. Interestingly, only three respondents (4 %) indicated support for the discussion of R/S issues during a genetic counseling session without any qualifications in open-ended responses. Just under half of respondents (49.5 %) expressed some level of support in one or more open-ended responses or indicated they would be "ok" with having a genetic counselor ask their patient if they wanted to discuss any R/S issues. However, these respondents also expressed some ambivalence or concern in at least one or more open-ended responses, as illustrated previously. For example, they felt religion and/or spirituality should only be discussed when the patient and GC shared similar religious beliefs or if they could be certain the GC would respect the patients' beliefs. Many respondents' (45 %) open-ended responses were consistent with the belief that a genetic counseling session was not an appropriate time to raise the topic of religion and/or spirituality. This was either because they felt it was not relevant, they would be uncomfortable, and/or they believed it should only be discussed if a patient is the one who raises the topic.

Discussion

Genetic Counseling Practice Implications

In recent years, many advocates within and beyond religious institutions and medical organizations have suggested incorporating R/S discussion into medical activities (Anderson 2009; The Joint Commission 2010; United States Conference of Catholic Bishops 2009). However, debates continue about the potential usefulness of such incorporation in relation to patient outcomes and experiences (Cragun et al. 2009; Reis et al. 2007; White 2009). Within these debates, patient perspectives on incorporating religion and/or spirituality into healthcare provision are sparse, and we found no research evaluating outcomes of such discussions. As a result, healthcare providers, including but not limited to GCs, are typically making decisions about broaching R/S issues on a case by case basis without evidence concerning the impact it may have.

By analyzing the attitudes and opinions of genetic counseling patients in open-ended responses, we demonstrated some nuances and variations in the ways people think about R/S discussions in the genetic counseling context. While our sample does not allow for broad generalizations, even the minority of respondents who clearly supported R/S incorporation into genetic counseling expressed potential concerns.

Performing comprehensive R/S assessments may be useful for a subset of R/S patients, yet there are many potential problems with this type of assessment. For example, our data suggest addressing religion and/or spirituality could be seen as intrusive rather than beneficial. Additionally, the growing U.S. and world populations whom are nonreligious and nonspiritual would likely find such assessments both irrelevant and disrespectful because of how they privilege religion and/or spirituality over other potentially important cultural and social influences (Cragun 2015; Edgell et al. 2006; Hammer et al. 2012). Even among most of our primarily R/S respondents, addressing religion and/or spirituality was described as either irrelevant to genetic counseling or less important than discussions of medical and risk information. While a number of respondents reported ways R/S awareness might be useful on the part of GCs, many also expressed opinions that: 1) genetic counseling should be about science; 2) GCs are not qualified to discuss R/S issues; 3) patients who wanted R/S counseling had other outlets where they could get this need met by R/S professionals or others with more similar R/S beliefs; and/or 4) R/S discussions are more likely to be accepted if patients bring up the topic or in specific circumstances (e.g., when they are facing end-of life decisions).

The nuances we uncovered reveal there is always the potential for negative reactions whenever GCs broach R/S topics. Among both the R/S and the nonreligious/nonspiritual, the overwhelming perspectives suggest that incorporating religion and/or spirituality into genetic counseling could be more problematic than helpful. Additionally, many respondents advocated for the distinction between both training and practice of medical and R/S professionals, and several suggested outright opposition to any incorporation of religion and/or spirituality into genetic counseling. Overall, the entirety of the responses suggest GCs would be best equipped to help all their patients if they were simply prepared to listen, be supportive, and make referrals to individuals who are more qualified to discuss R/S beliefs when these issues come up in genetic counseling.

Ultimately, our findings favor tailored rather than uniform approaches wherein counselors omit R/S discussion unless it

is brought up by patients, and then GCs either discuss it upon patient request or provide referrals to R/S professionals depending upon the stated desires of a given patient. Even if GCs step back from routinely assessing or discussing R/S issues, there are other ways of eliciting and helping patients' meet their individualized needs. For example, GCs could routinely ask broader questions about how the patient has successfully dealt with difficult medical or emotional situations in the past or about what aspects of their life they consider important in making decisions. If religion and/or spirituality helps them cope or are salient in their lives, these issues would likely come up in responses to these types of broader questions. The benefit of this broader approach is that there would be essentially no risk of offending patients or making them uncomfortable because all individuals could simply identify coping or decision-making strategies that are most salient to their beliefs and/or personal circumstances.

Our data are not alone in supporting this approach. A prior Master's thesis published only online reported results of a cross-sectional survey of 43 prenatal patients and 103 pediatric patient caretakers at three Midwestern U.S. genetics clinics (Fick 2006). Although 75 % of respondents in that study considered themselves to be spiritual, nearly 78 % rated spirituality as being of low relevance to clinical genetics visits and only a third wanted to be asked about spirituality during the visit. The minority (22.5 %) who perceived spirituality to be relevant to genetics visits were significantly more likely to want providers to ask about spirituality during a visit and want provider-patient beliefs to be similar. In contrast, the non-spiritual minority tended to be uncomfortable with the idea of being asked about spiritual issues as part of genetic counseling.

MacLean et al. (2003) investigated patients' views regarding physicians approaching R/S topics at primary care appointments across the U.S. In their study, a majority of patients (66 %) wanted their physician to be aware of their R/S beliefs, which is greater than the number of respondents in our study who wanted their GC to be aware of their R/S beliefs. However, like our findings, MacLean and colleagues found religion and/or spirituality was not generally a priority given that only 10 % reported being willing to trade time spent discussing medical issues in order to address R/S issues. The finding that context may influence the relevance of R/S issues, which we observed, is also illustrated by MacLean's findings demonstrating variation in the percentage of patients who wanted their physician to address R/S issues (i.e., 33 % among those presenting for a routine office visit, 40 % for those hospitalized but not near death, and 70 % for those receiving end-of-life care).

Our findings, along with the other two studies we described assessing patients' opinions on R/S issues, thus stand in opposition to the Joint Commission for Accreditation, Healthcare, and Certification's suggestion for incorporating R/S discussion into health systems and protocols (The Joint Commission 2010). While there are some cases within medicine where the incorporation of R/S discussions or assessments may be useful for patients, data on this topic reveal many patients would not find it helpful. The accumulation of this data suggest that although GCs should be prepared for R/S discussions initiated and driven by patients, evidence fails to support the routine incorporation of R/S assessments into genetic counseling practice. This appears consistent with what many GCs are already doing as evidenced by survey findings where GCs reported being more likely to assess religion and spirituality if the patient brought the subject up first, when abortion is presented as an option that some individuals consider, or in end-of-life discussions (Reis et al. 2007).

Study Limitations

Like any emerging area of research, our study has some important limitations that must be considered when interpreting our results. First, we utilized a convenience sample of anonymous respondents who are primarily White, female, and R/S, and thus we are incapable of making substantive generalizations from this population. As a result our findings should not be interpreted as representative of any given patient population and there is no way to know if the themes we found are inclusive of all perspectives on this issue. Although other populations may not reveal widespread patient concerns about the incorporation of R/S issues in genetic counseling contexts, this was the case for our sample as well as the only other study we identified that elicited patient opinions related to genetic counseling and R/S issues. Finally, despite our use of qualitative responses from 67 respondents, we do not have enough follow up questions to claim that responses represent the process whereby patients make sense of R/S issues related to genetic counseling. Rather, what we are able to provide is a snapshot of respondents' responses to the possibility of incorporating R/S discussions into genetic counseling. In addition, it is plausible that respondents' pre-conceived notions of what discussion and addressing R/S issues would entail may account for some of the negative reactions. Future studies may assist in clarifying this potential misunderstanding.

Research Recommendations

Our findings call for a more systematic examination of patient perspectives on whether or not religion and/or spirituality should be discussed or used within a variety of different medical contexts before R/S assessment or discussion is broadly or routinely incorporated into medical encounters.

Conclusion

Important deliberation regarding the prominence and influence of religion and spirituality in society fuels debate about what

role, if any, R/S assessment and discussion should play in medical practice. Understanding whether or not religion and/or spirituality may be usefully incorporated into a given medical service requires exploring the ways patients would react to such incorporation. This paper looked at patients' perspectives of discussing religion and/or spirituality in genetic counseling sessions. We found that respondents' responses were nuanced and varied, but ultimately, the routine incorporation of religion and/or spirituality into genetic counseling was not a priority for most respondents and posed a number of concerns. Since incorporating R/S discussions into practice will only be useful if it meets patient needs, our findings suggest that the approach, reported by most GCs in a prior study (Reis et al. 2007), whereby GCs discuss R/S issues primarily if the topic is raised by the patient, may be the preferred approach.

Following our respondents' views, we suggest that although awareness of patients' R/S beliefs by healthcare providers may be appreciated in medical settings, patients' R/S needs are better met indirectly by helping them connect with someone who shares similar beliefs with the patient and/or someone who specializes in helping patients deal with R/S matters. Most importantly, this approach will leave more time in clinic to focus on the scientific and medical aspects of the patient's care, which appears to be the primary reason why patients attend genetic counseling.

Compliance with Ethical Standards

Conflict of Interest Amanda Bartenbaker Thompson, Deborah Cragun, J. E. Sumerau, Ryan T. Cragun, Vanessa De Gifis, and Angela Trepanier declare that they have no conflict of interest.

Human Studies and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all respondents for being included in the study. This study was approved by the Wayne State University Institutional Review Board and conducted accordingly.

Animal Studies No animal studies were carried out by the authors for this article.

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