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Spiritual Exploration in the Prenatal Genetic Counseling Session

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SPIRITUAL EXPLORATION IN THE PRENATAL GENETIC COUNSELING SESSION

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A

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Religion and spirituality are important components of many individuals' lives, and spiritual needs may present among persons receiving medical care. Spirituality has been demonstrated to be significant in the coping of women experiencing pregnancy complications (Breen et al. 2006; Price et al. 2007). To characterize the manner in which prenatal genetic counselors might address spiritual issues with their patients, we surveyed 283 patients receiving prenatal genetic counseling using the Brief RCope and a series of questions that examined interest in spiritual exploration. Counselors were concurrently surveyed to identify the spiritual language used within the session and the counselor's perceived importance of religion/spirituality to the patient. Genetic counselors were significantly more likely to identify a patient as using R/S when the patients used spiritual language ($p<0.001$) and anecdotally when religious clothing or jewelry were present. Nearly 67% of patients reported that they felt comfortable sharing their faith as it relates to decision making in their pregnancy, and 92.8% reported one or more methods of positive religious coping (Brief RCope PRC median = 23). Less than 25% reported a desire for overt religious actions such as prayer or exploration of holy texts within the genetic counseling session. Therefore, most patients' desires for discussion of spirituality in the decision making and coping processes are in line with a genetic counselor's scope of practice, and thus counselors should feel empowered to incorporate spiritual exploration into their patient conversations.

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ABBREVIATIONS

PRC – positive religious coping

NRC – negative religious coping

R/S – religion/spirituality

BACKGROUND

Religiosity and spirituality are important components of many Americans' lives, with as many as 86% of Americans reporting a belief in God or a universal spirit according to Gallup polls (Gallup, Inc., 2015). Although easily confused, religiosity and spirituality have distinctly unique implications. Religiosity is primarily understood as one's adherence to a denominational belief system or practice, and can be characterized by a person's obedience to an explicit set of religious rules or parameters (Breen et al. 2006; Koenig, King, & Benner Carson 2012). A person might be described as more or less religious based upon how many times he or she attended religious services or participated in religious activities such as worship, prayer, or other religious actions (Koenig, King, & Benner Carson 2012). In contrast, spirituality is widely-acknowledged to have a broader definition than religiosity in which both religious and nonreligious perspectives are encompassed, as spirituality is not restricted by the boundaries of any one religious tradition and is frequently a self-defined concept (Breen et al. 2006; McCarthy Veach et al. 2003; Price et al. 2007; Ramondetta et al. 2013). Spirituality often centers on the search for meaning or purpose in life, and spiritual beliefs and practices aid a person in looking outside of the self for support and/or guidance in crisis situations (Breen et al. 2006; D'Souza 2007; Seth et al. 2011; Weil 2000).

Religiosity and spirituality are also considerations in the practice of medicine, as medicine aims to care not only for a person's physical or biological needs, but also a person's psychological, social, and spiritual needs. As such, many health care organizations identify with a holistic approach to health care that incorporates a spiritual dimension of helping people find meaning, hope, and wholeness in their life, even in times of illness (Byrne 2007; Saguil & Phelps 2012). Previous research has demonstrated that many physicians view spiritual care as part of their responsibility (Ramondetta et al. 2013; Tanyi et al. 2009). Yet, the execution of such care is difficult for many medical providers due to a lack of understanding of the spiritual issues encountered by their patients (Anderson 2009; Büssing et al. 2013; Breen et al. 2006; McEvoy et al. 2010; Price et al. 2007; Ramondetta et al. 2013; Reis et al. 2007).

Although providers may be hesitant to initiate discussion of spirituality, many patients welcome such conversation (Balboni et al. 2013; McEvoy et al. 2010; Reis et al. 2007; Tanyi et al. 2009). A study of 456 outpatients at six different academic medical centers found that 33% of participants wished for their physician to ask them about their religious beliefs, and 19% of participants wished for their physician to pray with them. These numbers increased with theoretical increased severity of illness, with 70% wishing for their physician to ask them about their beliefs and 50% wishing for the physician to pray with them in near-death situations (MacLean et al. 2003). However, a significantly higher portion of patients have been demonstrated to desire a discussion of religious or spiritual beliefs with their physician than those who actually receive such a dialogue (Ellis et al. 2013). Balboni et al. (2013) found that while nurses and physicians in the oncology setting reported providing spiritual care for 31% and 24% of their patients, respectively, only 13% of patients reported receiving spiritual care from their nurses, and only 6% reported receiving spiritual care from their physicians.

Spirituality is important to, and frequently employed by, women experiencing pregnancy complications. Pregnancy itself has been described as a spiritual experience due to the connection formed between the woman and her baby prenatally (Hall 2001; Johnson 2001). This spiritual relationship is threatened when complications arise in pregnancy, and the subsequent search for meaning experienced by many women reveals spirituality as a common form of coping in this population (Breen et al. 2006; Price et al. 2007). Spiritual coping was seen as the most frequently used style of coping in a study of 321 English-speaking pregnant women of varying medical risk, and was noted to be seen most commonly in early and mid-pregnancy, when primary fears centered on uncontrollable events such as miscarriage (Hamilton & Lobel 2007). A qualitative study of clinicians and clergy familiar with providing service to patients in high-risk pregnancies found that faith was reported to be a frequent and useful finding in their patients as it aided in coping (Bartlett & Johnson 2009). Yali and Lobel (1999) found prayer and positive reappraisal to be the most frequently reported coping tactics among women with high risk pregnancies. Furthermore, reliance on spiritual beliefs and participation in spiritual practices has been observed to

increase with increasing complications in pregnancy (Price et al. 2007). One study examining religiosity and spirituality in a high-risk population of Latina patients found faith and beliefs to be a clear source of comfort and nourishment for these women (Seth et al. 2011). A qualitative study of 130 pregnant women that asked how faith or spirituality impacted their pregnancy revealed that these women commonly found faith to provide guidance and support, protection, communication with God, strength, and help in making difficult choices (Jesse, Schoneboom, & Blanchard 2007). A patient's spiritual beliefs may provide comfort and reconciliation that could help ease difficult decisions (Anderson 2009; Ramondetta et al. 2013; Seth et al. 2011).

Acknowledging religion and spirituality as a resource in pregnancy can open conversational doors within the genetic counseling session (Anderson 2009; Bartlett & Johnson 2009; Geller et al. 2009). Although not all patients will overtly make known their wish for a discussion of spiritual matters, many patients express this desire through the incorporation of subtle spiritual language into their conversations (Byrne 2007; Koenig & Brenner Carson 2004; McEvoy et al. 2010). Continuing the discussion of religiosity/spirituality with those patients who provide hints of their beliefs may not only enhance the experience of the encounter itself, but also establish a secure foundation should an abnormality indeed by found later in the pregnancy (Breen et al. 2006; Saguil & Phelps 2012; Seth et al. 2011).

Appropriate spiritual care, then, involves recognition and support of the religious and spiritual dimensions of the presenting situation (Balboni et al. 2013; Ramondetta et al. 2013). Providers are often unsure as to whom the responsibility of addressing spiritual needs and tending to spiritual care in the medical setting belongs. Many authors suggest that no one discipline should have a monopoly on nurturing patients' spiritual dimensions. Spiritual needs infiltrate so deeply into medical care that addressing these needs cannot be relegated solely to hospital chaplains or visiting clergy; instead, each practitioner can provide spiritual care according to their respective scopes of practice (Breen et al. 2006; Hodge et al. 2014; Puchalski et al. 2009). While the concern that this topic might be outside of the genetic counseling scope of practice has caused many counselors to avoid discussion of spirituality within

the session, avoidance may deny the patient the opportunity to explore the ways in which spirituality affects the current situation (Byrne 2007; LeRoy et al. 2010; Reis et al. 2007). Therefore, it may behoove genetic counselors to be prepared to discuss spirituality as it relates to a pregnancy (Weil 2000).

While the importance of spirituality in pregnancy is well established, little is known about the extent to which prenatal patients desire their genetic counselors to be involved in discussing matters of religiosity/spirituality in their pregnancy, or whether genetic counselors correctly and consistently identify religious/spiritual needs in their patients (Cragun et al. 2009; White 2009). Therefore, this study aimed to assess patient interest in the discussion of spiritual needs in the prenatal genetic counseling session and to compare the perceived importance of religion/spirituality between prenatal genetic counselors and their patients in order to help genetic counselors better appreciate and address spiritual needs.

METHODS

Participants

English speaking and Spanish speaking women who were at least 18 years old having prenatal or preconception genetic counseling at one of seven University of Texas Medical School at Houston, Department of Obstetrics, Gynecology, and Reproductive Sciences, Division of Maternal Fetal Medicine affiliated high-risk pregnancy clinics or one of seven Baylor College of Medicine, Department of Obstetrics and Gynecology affiliated high-risk pregnancy clinics were eligible for participation. This study was approved by the institutional review boards at the University of Texas Health Science Center (IRB #HSC-MS-14-0497), Memorial Hermann Healthcare System (IRB #HSC-MS-14-0497), Harris Health System (IRB #14-09-0928), and Baylor College of Medicine (IRB #H-35666). Eligible women were given a letter of invitation by the genetic counselor or genetic counseling student at the conclusion of the genetic counseling appointment. Returning the letter of invitation with the completed survey served as informed consent in the study. Participants were recruited between July 31, 2014 and January 19, 2015. Specific dates varied by site based on receipt of IRB approval.

Instrumentation

Eligible participants were provided a letter of invitation (Appendix A) and an anonymous survey (Appendix B). The patient survey was coded to match the corresponding genetic counselor survey (Appendix C) that contained clinical characteristics, a Likert scale assessing the counselor's perception of the importance of spirituality to the patient, and a word-bank of religious or spiritual words to denote any spiritual language employed during the session. This survey was anonymously completed by a certified genetic counselor or her genetic counseling student, depending upon who acted as the primary counselor. The patient's survey contained demographic information, the Brief RCope survey to evaluate the use of positive and negative religious coping during pregnancy, and Likert scales assessing the participant's feelings regarding the importance of spirituality in their life, its utility in decision making during

pregnancy, and whether they felt their spiritual needs were met within the session. The Brief RCope is a validated measure of religious coping designed to assess religious coping with major life stressors, and was used with permission (Pargament, Feuille, & Burdzy, 2011; K. Pargament, personal communication, May 11, 2014).

Data Analysis

The two surveys were matched together to compare the answers of the patients and counselors, and this data was entered into a Microsoft Access file. STATA 13 software was used to perform statistical analysis. Similar indications for counseling were grouped according to their commonalities, and counselor- and patient-provided qualitative responses were analyzed for themes. Demographic and clinical characteristics were analyzed using descriptive statistics, while categorical variables from Likert scale questions regarding genetic counseling and religion/spirituality were analyzed using Chi square and Fisher's exact tests. The positive religious coping (PRC) and negative religious coping (NRC) scores were compared across the different Likert strata for the genetic counseling questions and across the indications for genetic counseling using Kruskal-Wallis tests. Respondents' PRC scores were calculated as the sum of questions 1-7 in the Brief RCope, while NRC scores were calculated as the sum of questions 8-14. PRC and NRC scores were not calculated for individuals missing at least one PRC or NRC question, respectively. For final analysis, patients were excluded if they did not have a calculated PRC and NRC score, and did not answer any of the Likert scale genetic counseling-focused questions provided in Section III.

RES ULTS

Twenty-three certified genetic counselors, 8 second-year genetic counseling students, and 3 first-year genetic counseling students were available for anonymous participation in the study. The majority of surveys (85%) were completed by certified genetic counselors. There was no statistically significant difference identified in how the patient perceived that the primary counselor recognized her faith and its impact on the pregnancy situation ($p = 0.185$), or in whether the patient felt her spiritual needs had been met within the session ($p = 0.986$) between certified genetic counselors and genetic counseling students. Therefore, participants were not stratified by type of genetic counselor in reporting subsequent results.

A total of 2,299 patients were seen at the recruitment sites during the study period. Of these, 423 patients (18.4%) were offered the opportunity for participation. One patient was excluded due to eligibility, and 139 (23.1%) were excluded due to missing data. The final sample size available for analysis was 283 (12.3% of all patients seen during the study period and 66.9% of all patients who were offered the study). Refer to Figure 1 for additional details.

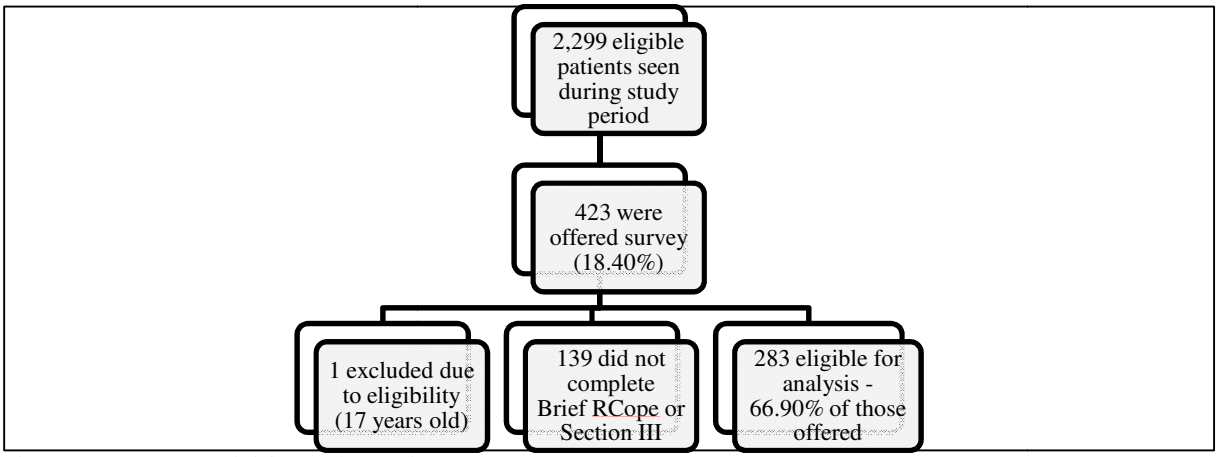

Figure 1: Data acquisition schematic

To assess the external validity of our dataset, the demographic distribution with respect to age, ethnicity, and indication of advanced maternal age of the study subjects at each of the UT affiliated sites were compared to the total patient population seen at each of the UT affiliated sites during the study period, and were found to be not significantly different ($p > 0.05$ for all above factors at each site).

However, patients with ultrasound abnormalities of any severity made up a significantly lower proportion of participants compared to the number of patients with ultrasound abnormalities seen in the UT clinics (p <0.001). Furthermore, there were no differences with respect to ethnicity and indication of ultrasound anomaly at the Baylor affiliated clinics. However, study subjects from one site were slightly older than the patients seen at that clinic (34.8 vs. 31.8 years, respectively; $p = 0.006$).

Demographics

Eighty-six percent of all surveys were completed in English. The most frequently reported ethnicities were Hispanic (37.2%) and Non-Hispanic white (36.1%). The majority of respondents (62%) were age 34 and older, thus expected to be of advanced maternal age at the time of delivery. Approximately 74% of patients reported completing at least some college, and 71.3% of patients were married. The most frequently reported religious affiliations were "Christian – other" (30.5%), "Roman Catholic" (25.7%), and "Baptist" (13.4%), although over 17 different religious affiliations were reported. Table 1 contains a complete list of participant characteristics.

Table 1 Summary of participant characteristics (*n*=283)

Mean age	33.3 years		Relationship Status (*n*=275)	%	(*n*)
			Single	9.82	(27)
Ethnicity (*n*=274)	%	(*n*)	In a relationship	16.73	(46)
Non-Hispanic white	36.13	(99)	Married	71.27	(196)
Hispanic	37.23	(102)	Divorced	1.09	(3)
African American	19.34	(53)	Other	1.09	(3)
Asian/Pacific Islander	5.84	(16)			
Native American	0.36	(1)	Religious Affiliation (*n*=269)	%	(*n*)
Other	1.09	(3)	Agnostic	2.60	(7)
			Atheist	1.49	(4)
Education (*n*=272)	%	(*n*)	Baptist	13.38	(36)
Graduate/professional degree	19.49	(53)	Buddhist	2.23	(6)
Undergraduate/4-year degree	25.74	(70)	Christian Science	0.37	(1)
Some college or 2-year degree	28.31	(77)	Christian - other	30.48	(82)
Graduated high school or GED	16.18	(44)	Church of Christ	1.49	(4)
Some high school	9.19	(25)	Church of Jesus Christ of Latter-Day Saints (Mormon)	0.37	(1)
Never attended high school	1.10	(3)			
			Eastern Orthodox	1.49	(4)
Indication for Counseling (*n*=283)	%	(*n*)	Episcopalian/Anglican	0.37	(1)
Advanced maternal age only	44.52	(126)	Jehovah's Witnesses	1.12	(3)
Advanced maternal age & other	15.55	(44)	Jewish	1.49	(4)
Positive aneuploidy screen (biochemical or cell-free DNA)	11.66	(33)	Lutheran	1.12	(3)
			Methodist	4.46	(12)
Positive family history	8.83	(25)	Muslim	0.37	(1)
Ultrasound abnormality	5.30	(15)	Pentecostal/Charismatic	2.97	(8)
Carrier of genetic condition	4.59	(13)	Presbyterian	1.12	(3)
Other indication	3.53	(10)	Roman Catholic	25.65	(69)
Multiple indications (non-AMA)	3.89	(11)	Other	7.43	(20)
History of infertility/recurrent miscarriage	1.06	(3)			
No indication specified	1.06	(3)			

Advanced maternal age as the only indication was the most commonly reported indication for genetic counseling among this sample (44.52%). Other common indications included advanced maternal age and another indication (15.55%), positive biochemical and cell-free DNA screening results (11.66%), family history of a genetic condition or having a previous child with a genetic condition (8.83%), having an abnormality detected on ultrasound (5.30%), or being a carrier of a genetic condition (4.59%). The majority of patients in the sample whose indication was specified by the genetic counselor were being seen for only one indication (80.36%), and 19.64% of patients had two or more indications.

Counselor Perceptions & Spiritual Language

Genetic counselors reported their perceptions regarding the importance of religion/spirituality (hereafter, R/S) to the patient in 275 surveys. The most frequently reported perception was "uncertain" (36.7%). Approximately 29% of patient R/S was perceived as "moderately important," 17.5% was perceived as "absolutely essential," 15.6% was perceived as "not very important," and only 1.1% was perceived as "not at all important." Genetic counselors were significantly more likely to identify R/S as being important to patients who self-reported religion being important ($p = 0.003$). However, there was no relationship between genetic counselor's perceptions of R/S and patients who did not report religion as being important ($p = 0.164$).

Spiritual language was reported 314 times through the use of 24 different spiritual words or phrases, the most common of which were "God," "hope," "believe/belief," "faith," "trust," and "pray/praying for," as seen in Table 2.

Table 2 Reports of spiritual language (*n*=314)

Term	Number of reports
Allah	2
Believe/belief	35
Christian	5
Church/mass	4
Blessed/blessing	10
Destiny/fate	3
Faith	32
Gift from God	10
God	49
God's hands	14
God's plan	3
God's will	14
Heaven	1
Hell	1
Hope	41
Jesus/Christ	1
Miracle	3
Pastor/priest	2
Pray/praying for	30
Religion/religious	6
Sin	1
Spirit/spiritual	1
Trust	32
Other	13
Terms per session	Number of reports
None	144
One	60
Two	34
Three or more	45

Spiritual language was reported as present in 50.88% of genetic counseling appointments; however, the number of terms used within each session ranged from 1-10 terms. Of those who employed spiritual language, 21.20% used one term, 12.01% used two terms, and 15.90% used three or more terms. Counselors were significantly more likely to rate a patient's R/S as important with an increasing number of terms used within the session (p <0.001). In sessions in which no spiritual terms were reported, 63.04% of counselors reported that they were uncertain regarding the patient's importance of R/S, and only 10.14% reported perceiving R/S as important.

Brief RCope

Out of the 283 patients eligible for analysis, 264 had a PRC score and 276 had a NRC score. The median PRC score was 23 with a mean PRC score of 21.2 (SD: 6.43; range: 7-28). The median NRC score was 7 with a mean NRC score of 9.2 (SD: 3.89; range: 7-28). The vast majority of patients (92.8%) reported 1 or more PRC measures (score of 8 or higher); however, only 44.2% of patients reported 1 or more NRC measures (score of 8 or higher). Seventy-nine patients (29%) were identified as being in high spiritual struggle, as defined as having a NRC score of 10 or higher (Defense Centers of Excellence, 2015).

Genetic Counseling & Religion/Spirituality

The number of respondents answering individual questions in Section III ranged from 262-271. Eighty-five percent of respondents agreed or strongly agreed that religion or faith is an important part of their life, while 75.5% of respondents reported looking to their religion/faith in dealing with stressors, and 62.7% of respondents reported using their faith to make decisions in pregnancy. A significant association was found between the use of any spiritual terms used in the session and the incorporation of faith in pregnancy decision-making ($p = 0.002$). There was no statistically significant difference between those who used one term, two terms, or three or more terms in regards to the incorporation of faith in pregnancy decision making ($p = 0.313$). Only 23.05% of respondents indicated wanting to talk about their faith in the genetic counseling session, while 66.92% of respondents indicated that they were comfortable with sharing their faith and the way it influences their pregnancy decision-making. A significant association was demonstrated between individuals who used one or more spiritual terms and being comfortable sharing their faith in the context of their pregnancy ($p <0.001$). Furthermore, a significant association was also demonstrated with increasing number of spiritual terms and being comfortable sharing faith in a pregnancy context ($p = 0.008$). Nearly 36% of respondents reported that their genetic counselor recognized their faith and its impact on their pregnancy, and 53.1% of respondents reported that they were

happy with the way that the genetic counselor addressed their faith and its relation to their pregnancy. Of those individuals who reported happiness with their genetic counselor's methods of addressing faith, 60.43% felt that the conversation they had with their genetic counselor met their spiritual needs for the appointment (p <0.001). Fifty-nine percent of respondents indicated that they would not have liked the genetic counselor to pray with them in the session, and 27.61% of respondents were uncertain. Similarly, 64.18% of respondents did not wish for the genetic counselor to explore Scripture or other holy texts in the session, and 57.68% did not want reference materials or spiritual resources provided for exploration outside of the genetic counseling appointment. Only 15.30% of patients indicated that they would like the genetic counselor to share her faith background or faith experience with the patient. Overall, 44.70% of patients felt that their conversation with the genetic counselor met their spiritual needs for the appointment, while 29.55% of patients remained uncertain about their spiritual needs being met. Of the patients who reported that their spiritual needs were met, 73.04% were happy with the way that their genetic counselor addressed their faith and its relation to the pregnancy (p <0.001). See Table 3 for a full breakdown of these results.

Table 3 Spiritual utilization/exploration and genetic counseling

	Strongly disagree	Disagree	Uncertain	Agree	Strongly Agree
My religion or faith is an important part of my life (*n*=271)	14 (5.2%)	8 (3.0%)	19 (7.0%)	95 (35.1%)	135 (49.8%)
I look to my religion/faith for help in understanding and dealing with stressors (*n*=269)	22 (8.2%)	18 (6.7%)	26 (9.7%)	104 (38.7%)	99 (36.8%)
I use my faith to make decisions in my pregnancy (*n*=268)	37 (13.8%)	22 (8.2%)	41 (15.3%)	79 (29.5%)	89 (33.2%)
I would like to talk about my faith in the genetic counseling session (*n*=269)	70 (26.0%)	67 (24.9%)	70 (26.0%)	40 (14.9%)	22 (8.2%)
I am comfortable sharing my faith and the way my faith influences my life, family, and pregnancy (*n*=269)	26 (9.7%)	21 (7.8%)	42 (15.6%)	101 (37.6%)	79 (29.4%)
The genetic counselor recognized my faith and the way that it affects my life, family, and pregnancy (*n*=264)	38 (14.4%)	27 (10.2%)	104 (39.4%)	52 (19.7%)	43 (16.3%)
I am happy with the way the genetic counselor addressed my faith and the way that it relates to my pregnancy/current situation (*n*=262)	24 (9.2%)	7 (2.7%)	92 (35.1%)	76 (29.0%)	63 (24.1%)
I would have liked the genetic counselor to pray with me in the session (*n*=268)	90 (33.6%)	69 (25.8%)	74 (27.6%)	24 (9.0%)	11 (4.1%)
I would have liked the genetic counselor to explore Scripture or other holy texts with me in the session (*n*=268)	98 (36.6%)	74 (27.6%)	72 (27.2%)	13 (4.9%)	10 (3.7%)
I would like it if I was given reference materials or spiritual resources to explore outside of the genetic counseling session (*n*=267)	88 (33.0%)	66 (24.7%)	50 (18.7%)	44 (16.5%)	19 (7.1%)
I would like it if the genetic counselor shared her own faith background or faith experience (*n*=268)	86 (32.1%)	62 (23.1%)	79 (29.5%)	28 (10.5%)	13 (4.9%)
What the genetic counselor and I talked about met my spiritual needs for this appointment (*n*=264)	37 (14.0%)	31 (11.7%)	78 (29.6%)	75 (28.4%)	43 (16.3%)

Genetic counseling and positive/negative religious coping

Significant associations were found between increasing PRC scores and the importance of religion/faith, using religion/faith in stress or pregnancy decision making, wishing to talk about faith in the genetic counseling appointment, satisfaction with the genetic counselor's recognition and addressing of the impact of faith, and desire for overt religious actions in the genetic counseling appointment (Table 4). A significant association was also discovered between increasing NRC scores and the desire for overt religious actions in the genetic counseling appointment, specifically praying (p=0.043), exploring Scripture (p=0.005), receiving spiritual reference materials or resources (p=0.025), and discussing the genetic counselor's faith background (p=0.045), (Table 5).

Table 4 Positive religious coping and genetic counseling

	PRC Score – n; median (interquartile range)					*p* value
	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree	
My religion or faith is an important part of my life	14; 7 (7-8)	7; 8 (7-12)	19; 14 (11-15)	92; 22 (16-25)	125; 25 (22-28)	<0.001
I look to my religion/faith for help in understanding and dealing with stressors	21; 7 (7-8)	17; 13 (11-20)	26; 15.5 (12-21)	100; 23 (19-25)	92; 26 (23-28)	<0.001
I use my faith to make decisions in my pregnancy	36; 8 (7-16.5)	21; 15 (12-20)	38; 19 (15-24)	76; 23 (20.5-26.5)	83; 27 (24-28)	<0.001
I would like to talk about my faith in the genetic counseling session	67; 18 (8-25)	63; 21 (15-24)	67; 24 (21-27)	39; 26 (23-28)	20; 28 (25-28)	<0.001
I am comfortable sharing my faith and the way my faith influences my life, family, and pregnancy	25; 8 (7-21)	20; 15 (11.5-18)	42; 21.5 (15-24)	95; 23 (19-26)	73; 27 (24-28)	<0.001
The genetic counselor recognized my faith and the way that it affects my life, family, and pregnancy	36; 15.5 (7-22.5)	26; 18 (14-23)	99; 23 (19-25)	49; 25 (18-27)	41; 27 (25-28)	<0.001
I am happy with the way the genetic counselor addressed my faith and the way that it relates to my pregnancy/current situation	24; 17 (7-24)	7; 24 (8-25)	85; 21 (17-25)	73; 23 (18-25)	60; 27 (23.5-28)	<0.001
I would have liked the genetic counselor to pray with me in the session	88; 20.5 (10-25)	62; 21 (16-25)	71; 24 (21-27)	24; 26.5 (23-28)	10; 28 (27-28)	<0.001
I would have liked the genetic counselor to explore Scripture or other holy texts with me in the session	94; 20.5 (10-26)	68; 21 (15.5-24)	71; 25 (23-27)	13; 24 (23-28)	9; 28 (27-28)	<0.001
I would like it if I was given reference materials or spiritual resources to explore outside of the genetic counseling session	84; 19 (9.5-25)	61; 21 (16-24)	48; 25 (23-27)	43; 25 (21-28)	18; 27 (24-28)	<0.001
I would like it if the genetic counselor shared her own faith background or faith experience	83; 19 (10-25)	58; 21.5 (16-25)	75; 24 (22-27)	27; 25 (20-28)	12; 27 (23-28)	<0.001
What the genetic counselor and I talked about met my spiritual needs for this appointment	37; 19 (10-25)	31; 23 (17-25)	74; 24 (19-27)	70; 22.5 (17-26)	39; 26 (20-28)	0.037

Table 5 Negative religious coping and genetic counseling

	NRC Score – n; median (IQR)					*p* value
	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree	
My religion or faith is an important part of my life	14; 7 (7-7)	7; 7 (7-9)	19; 9 (7-15)	92; 8 (7-10)	132; 7 (7-10)	0.056
I look to my religion/faith for help in understanding and dealing with stressors	21; 7 (7-7)	17; 7 (7-9)	26; 9 (7-13)	101; 7 (7-10)	98; 7 (7-10)	0.116
I use my faith to make decisions in my pregnancy	36; 7 (7-10)	21; 8 (7-10)	40; 7 (7-10.5)	77; 7 (7-10)	87; 7 (7-10)	0.952
I would like to talk about my faith in the genetic counseling session	68; 7 (7-9)	65; 7 (7-11)	70; 8 (7-10)	39; 7 (7-10)	22; 8 (7-13)	0.324
I am comfortable sharing my faith and the way my faith influences my life, family, and pregnancy	25; 7 (7-9)	21; 8 (7-13)	42; 8 (7-10)	98; 7 (7-10)	77; 7 (7-9)	0.133
The genetic counselor recognized my faith and the way that it affects my life, family, and pregnancy	37; 7 (7-9)	26; 7.5 (7-10)	102; 8 (7-11)	51; 7 (7-10)	43; 7 (7-10)	0.593
I am happy with the way the genetic counselor addressed my faith and the way that it relates to my pregnancy/current situation	24; 7 (7-9)	7; 7 (7-12)	87; 7 (7-10)	76; 7 (7-10.5)	63; 7 (7-12)	0.715
I would have liked the genetic counselor to pray with me in the session	89; 7 (7-9)	66; 7 (7-10)	73; 7 (7-9)	24; 10 (7-12)	11; 8 (7-14)	0.043
I would have liked the genetic counselor to explore Scripture or other holy texts with me in the session	96; 7 (7-9)	72; 7 (7-10)	72; 7.5 (7-10)	13; 10 (9-17)	10; 7.5 (7-13)	0.005
I would like it if I was given reference materials or spiritual resources to explore outside of the genetic counseling session	86; 7 (7-9)	64; 7 (7-10)	49; 8 (7-11)	44; 8 (7-11)	19; 10 (7-13)	0.025
I would like it if the genetic counselor shared her own faith background or faith experience	85; 7 (7-9)	60; 7 (7-10)	77; 8 (7-11)	28; 8 (7-12)	13; 9 (7-14)	0.045
What the genetic counselor and I talked about met my spiritual needs for this appointment	37; 7 (7-9)	31; 8 (7-10)	75; 8 (7-11)	73; 7 (7-10)	43; 7 (7-9)	0.347

When median PRC scores were compared with patient indications, those individuals with multiple non-AMA indications were found to have a significantly lower median PRC score (median =15) than persons receiving genetic counseling for other indications (p=0.0191). Furthermore, a significant difference was also found between the median NRC scores and patient indications, as persons whose only indication was infertility or recurrent miscarriage had a significantly higher NRC score than scores found in other groups (p=0.0214). Of note, there were only three individuals in the category of infertility or recurrent miscarriage as the only indication for genetic counseling. Refer to Figures 2 and 3 for additional details.

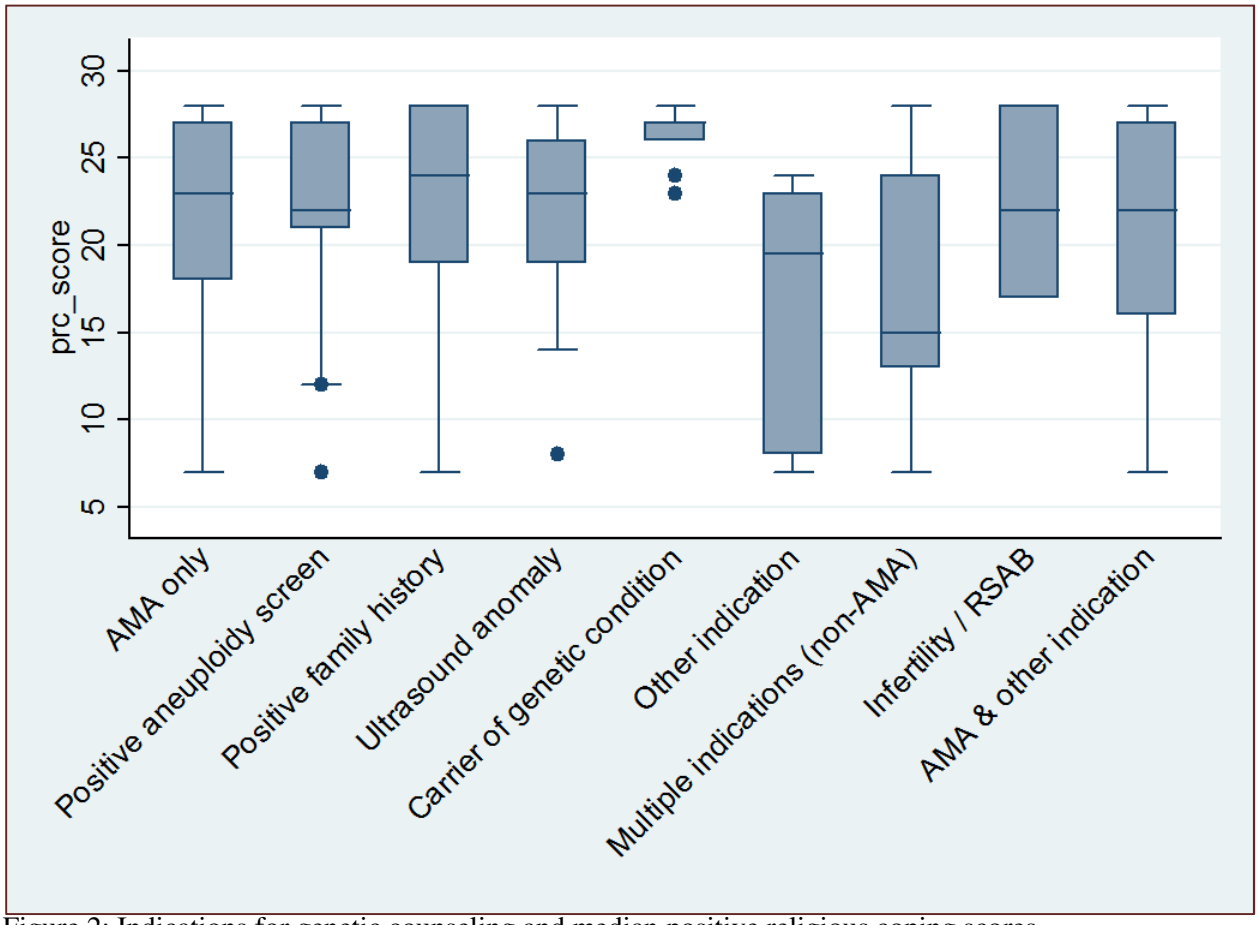

Figure 2: Indications for genetic counseling and median positive religious coping scores

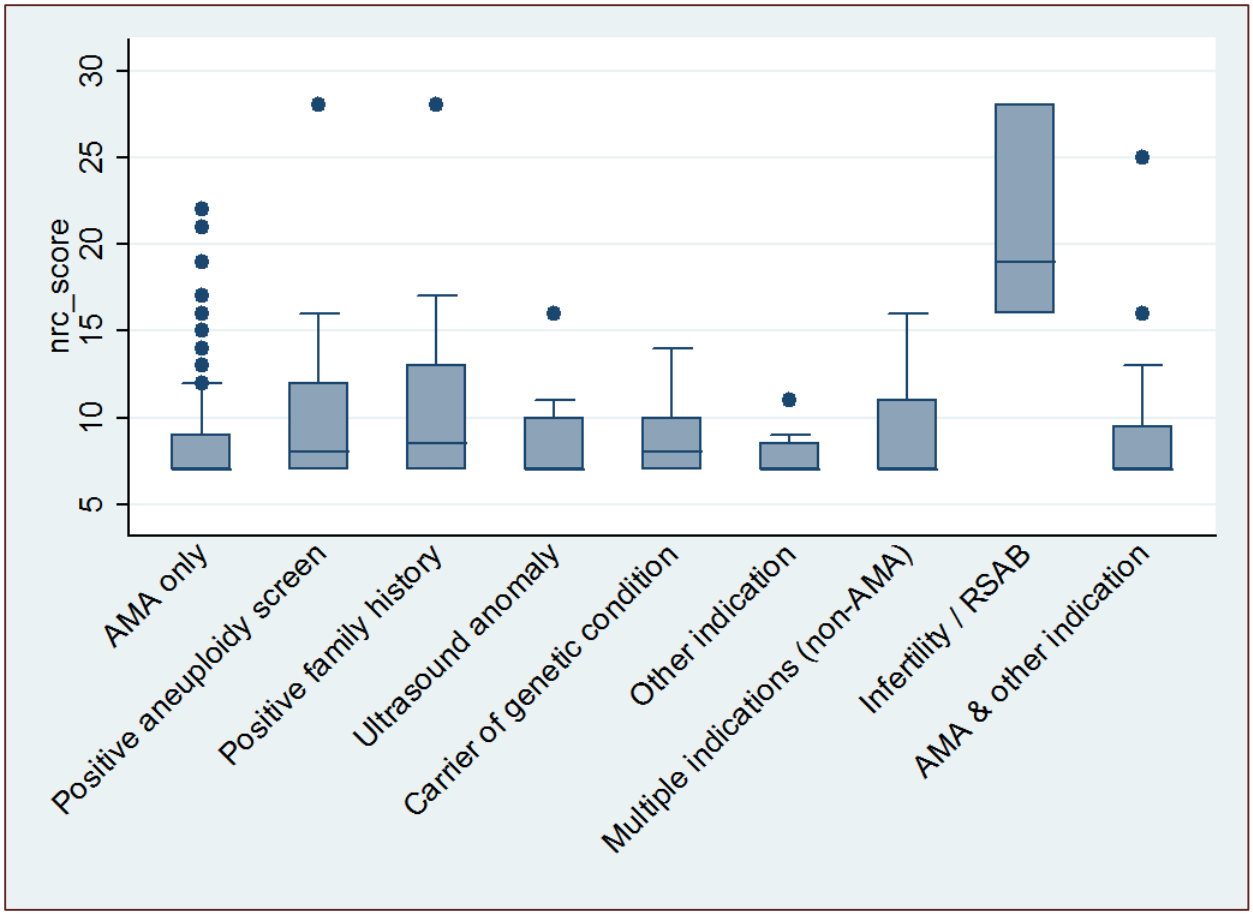

Figure 3: Indications for genetic counseling and median negative religious coping scores

Patient Comments

Forty-six patients provided feedback in the space provided for additional comments. The themes emerging from these responses were categorized into six groups, which are as follows: 1) approve of R/S in genetic counseling session, 2) disapprove of R/S in genetic counseling session, 3) no expectations for R/S in genetic counseling session, 4) not applicable in my genetic counseling session, 5) satisfaction with genetic counselor/genetic counseling session, and 6) other comments. See Table 6 for selected responses indicative of the themes from each of the above categories.

Table 6 Patient response themes

Approve of R/S in genetic counseling session

- "My uncertainty for questions 8-11 [overt religious action questions] are because I believe it should happen naturally. I welcome prayer and literature about my faith but I would not force that type of counseling."
- "Being able to relate faithfully and religiously helps build a relationship w/ our counselor during this emotional yet exciting journey."
- "Build an understanding of how the divine entity has control in all creation (including conception and genetics)."
- "So long as the initial genetic questions I had were answered (because I had a lot of them) I think it would be great to be able to freely express her faith. To pray with me…yes! That's paramount! Not all will be receptive, but we're called to be fishers of men."

Disapprove of R/S in genetic counseling session

- "If I'm in need of genetic counseling I appreciate that information. I have a relationship with God and would not really want to discuss my faith while dealing with another situation at hand."
- "…there might be people who would probably benefit for a more spiritual approach, however I think I would find it uncomfortable, as well as belonging to a different domain, personally."
- "If I want to discuss God's path for my life, I would take the info from the genetic counselor to my pastor."
- "I do not feel, as a Presbyterian minister, that a genetic counselor is at all qualified to discuss faith. If one is trained in 'active listening,' I feel that would be helpful, but a genetic counselor should NOT pray, explore scripture, or give spiritual reference material. A chaplain or the patient's pastor should be called."

No expectations for R/S in genetic counseling session

- "I wouldn't expect a genetic counselor to address spiritual aspects with me. I wouldn't mind it – but I separate doctor's office w/ my faith/church."
- "I have no expectations of talking about God with any medical employees. I have other outlets for that but if they mention God or faith it is nice and welcome."
- "Not sure it is necessary for genetic counselor to address mine or their spiritual beliefs as they may differ greatly. I just appreciate the respect of how my beliefs affect my decisions."

Not applicable in my genetic counseling session

- "We didn't talk about faith in this visit, so in this instance my faith wasn't an issue. I did list it on my form that I am Christian."
- "We did not discuss faith/religion."

Satisfaction with genetic counselor/genetic counseling session

- "Counselor was very knowledgeable and met my expectations/needs regarding my pregnancy."

Other

- "God is good."
- "I am not strongly practicing the Buddhist religion. I was just raised as a Buddhist and am open to learning others."

DISCUSSION

Prenatal genetic counseling appointments can often be particularly emotional medical visits, and thus some patients may look to their spirituality or personal religious beliefs as they consider the possibility of adverse outcome in pregnancy. The results of this research provide a glimpse into the desires of patients receiving prenatal genetic counseling for spiritual exploration with their genetic counselor. On the whole, very few patients in this sample wished for overt religious actions such as engaging in prayer (13.06%), examining holy texts (8.58%), receiving spiritual resources (23.60%), or discussing another person's faith (15.30%) within the context of a genetic counseling appointment. Similarly, while the vast majority of patients reported that faith was an important part of their lives, less than a quarter of all patients reported a desire to discuss faith in their genetic counseling session. Overall, approximately 53% of patients reported that they were happy with the methods used by the genetic counselor in addressing their faith in relation to the pregnancy, and 60.43% of those who were happy with their genetic counselor's methods felt that the conversation they had with their genetic counselor met their spiritual needs for the appointment ($p < 0.001$). As approximately 67% of patients indicated that they felt comfortable sharing their faith and its impact on their life and/or pregnancy decision-making, including nearly 50% of those who had expressed not wanting to talk about their faith in the genetic counseling appointment, it appears that while a general discussion of faith is not often desired, a discussion of faith as it relates directly to the pregnancy is something that should not be discounted in the genetic counseling session.

Reis et al. (2007) previously found that many genetic counselors find barriers in performing a spiritual assessment within a genetic counseling appointment, including time constraints (45.7%), anticipated patient discomfort with the topic (27.6%), lack of patient-initiated discussion (14.9%), lack of perceived importance of spirituality to the patient (6.3%), and fear of spirituality/religious belief conflict between patient and counselor (4.7%). While the barrier of time will likely always be a limitation of genetic counseling, data from this study provides new perspective to many of these barriers. The

presence of 67% of patients in the current study reporting that they would, in fact, be comfortable discussing their faith as it relates to the pregnancy suggests that this topic is not a universally uncomfortable one, especially not if direct relevance to the pregnancy situation is demonstrated. This information is essential for genetic counselors, as it refutes the possible concern of genetic counselors postulated by Reis et al. (2007) that spiritual counseling might need to follow spiritual assessment in such a setting. Although the traditional definition of a formal spiritual assessment involves the process of active listening executed by a board-certified chaplain as defined by Puchalski et al. (2009), this study utilized a broader definition of spiritual assessment: a method by which a healthcare provider gains insight about a patient's spirituality and support systems. This is in keeping with the previously established terminology in the genetic counseling literature (Reis et al. 2007). With this distinction in mind, then, if spiritual assessment provides the opportunity for the provider to better understand the ways in which their patient wants R/S addressed in their care and/or the way R/S impacts coping and decision-making, then such an inclusion is far more likely to set the tone for a truly patient-centered genetic counseling experience than a theologically heavy conversation (Koenig 2007).

Nearly 93% of this high-risk pregnancy population reported one or more methods of positive religious coping to any degree, and the median positive religious coping score of 23 out of a possible 28 demonstrates that many patients are employing positive religious coping methods to a great extent. It is important for genetic counselors to be able to recognize when a particular coping method is being used in a pregnancy situation, as this can aid the counselor in identifying where the patient can find support within that situation (Djurdjinovic 2009). Just as recognizing traditional coping styles such as distancing, planning, avoidance, or using positive reappraisal is useful in genetic counseling, recognizing a patient's utilization of positive or negative religious coping can be helpful for a genetic counselor, as he or she can either support the patient's use of positive religious coping or consider making a referral for chaplaincy or pastoral services when a patient appears to be in spiritual struggle. It is interesting to note that a significant association was seen between increasing negative religious coping scores indicating spiritual

struggle and desire for overt religious actions such as prayer ($p = 0.043$), exploring holy texts ($p = 0.005$), receiving spiritual resources ($p = 0.025$), and discussing the faith of the genetic counselor ($p = 0.045$) within a genetic counseling session. These data suggest that persons who are experiencing high levels of spiritual struggle are more likely to be receptive to religious actions and would especially benefit from a referral to receive pastoral services. As increased positive religious coping scores were also seen to be associated with desire for prayer ($p <0.001$), exploration of holy texts ($p <0.001$), receiving spiritual resources ($p <0.001$), and discussing the faith of the genetic counselor ($p <0.001$), chaplaincy services might also be beneficial for those patients who appear to strongly rely on their faith as a source of coping, in addition to support from the genetic counselor.

In this study, genetic counselors were much more easily able to identify when R/S is important to a patient when the patient provided clues, such as the use of spiritual terms. The more spiritual terms that were used in a genetic counseling appointment, the more likely it was that the genetic counselor perceived R/S to be important to the patient ($p <0.001$). In addition, several genetic counselors mentioned nonverbal or contextual clues as being helpful in determining their perception of R/S in a patient. In the five different cases where a patient was mentioned to have worn clothing referencing ministry, worn jewelry with crosses or other Judeo-Christian religious icons, or brought a prayer book to the appointment, all patients strongly agreed that their faith or religion was an important part of their lives. While this information is too limited to infer direct relationships between wearing or bringing Judeo-Christian religious items into a genetic counseling appointment and the importance of that person's spiritual faith, it is reasonable for genetic counselors to incorporate such nonverbal clues into assessments of their patient's R/S. Furthermore, such items may provide a helpful starting point for initiating discussion of spiritual matters into pregnancy decision-making.

In contrast, this data appears to demonstrate that genetic counselors are hesitant to assess the importance of R/S to a patient until spiritual language is used, and is highlighted by some of the open-ended remarks from the counselors. "I put 2 at first [R/S not very important] but realized she didn't give

an indication to suggest it wasn't important, so changed to 3 [uncertain]," remarked one genetic counselor. In fact, when no spiritual terms were used, counselors reported they were uncertain of the importance of R/S to the patient 63.04% of the time. Many other open-ended comments mentioned that since spiritual language was not used within the session, matters of faith and spirituality were not addressed, indicating that many genetic counselors are waiting on patient cues. The traditionally nondirective nature of genetic counseling may tend to foster the belief that initiating a discussion of spiritual matters could be received as too forceful or unwelcome, and therefore, counselors may choose to wait until they are more confident that a patient might be receptive to such a discussion before performing a spiritual assessment or exploring spirituality. However, since some patients may not be aware of how their pregnancy could potentially be impacted by their spirituality or religious beliefs, it may be the responsibility of the genetic counselor to bring up this possibility in the genetic counseling session.

Genetic counselors are uniquely trained to present complicated medical information and prompt thoughtful discussion of difficult decisions within the context of patients' belief and value systems; therefore, understanding the role of spirituality or faith in a patient can help the counselor better facilitate all types of decision making and address their patients' concerns with greater empathy (Seth et al. 2011; Lemons et al. 2013). This study gives reassurance to those genetic counselors hesitant to perform spiritual assessments out of fear of where the conversation will lead since most patients do not appear to wish to discuss R/S issues that do not directly pertain to their pregnancy situation. However, the fact that genetic counselors were uncertain about the role of faith in many patients indicates that there is still improvement to be made in assessing and addressing R/S in current genetic counseling practices. Putting positive and negative religious coping into context as another coping mechanism that genetic counselors are trained to explore may aid genetic counselors in feeling comfortable with this topic.

Study Limitations

A significant limitation of this study was the small proportion of individuals who were given the opportunity to participate in the study (18.4% of the clinic population). Although we have demonstrated that our sample and the larger population are not statistically significantly different in terms of age, ethnicity, and AMA-status, the population is not representative of patients receiving prenatal genetic counseling for ultrasound abnormalities. At the majority of our sites, patients have genetic counseling followed by ultrasound, which allowed for time to complete the survey in between appointments. However, genetic counseling is the last appointment for most unexpected ultrasound results and the only appointment for preconception patients. Anecdotally, counselors mentioned that offering a survey seemed inappropriate for patients who had only just received news of abnormalities detected on ultrasound, and this patient population may have provided particularly interesting results. Logistical issues of specific clinic set-up may have impacted recruitment at certain sites with low offer rates. Additionally, Reis et al. (2007) suggested that many genetic counselors do not feel comfortable with performing spiritual assessments; therefore, it is possible that some counselors may not have felt comfortable distributing a survey about faith and religion. Measures of genetic counselor R/S were not obtained in this study and thus we cannot conclude whether this played a role. The possibility of an ascertainment bias is another limitation of this study, as counselors may have been more likely to offer a patient the survey if the patient indicated a religious affiliation on her intake form or used spiritual language within the genetic counseling appointment. However, since a 2014 survey of residents of the city of Houston found that 87.2% of individuals found religion to be at least somewhat important in their lives and 84.9% of respondents in our study reported that their faith was important in their lives, our sample does not appear to be significantly different from expected in terms of the importance of religion/faith (Rice University Kinder Institute for Urban Research, 2015). In addition, the study population was largely Christian in denomination, thus the results may not be applicable to those patients without Judeo-Christian affiliations.

Practice Implications

Our research demonstrates that not only do many individuals receiving prenatal genetic counseling employ positive religious coping measures, but also that many of these patients are comfortable with discussing their R/S in the context of their pregnancy. This information can empower prenatal genetic counselors to incorporate spiritual exploration into their patient conversations, as the discussion of faith as a coping mechanism or as something that could impact pregnancy decision-making is well within the genetic counseling scope.

While genetic counselors have accurate perceptions of patient R/S when their patients give clues about the importance of R/S in their life, such as using spiritual language or wearing religious clothing/jewelry, the refining of spiritual assessment skills so as to be able to elicit important information about R/S in relationship to the pregnancy when such clues are not provided is an area for improvement in genetic counseling. Such skills, including inquiring about the importance of R/S or what a person's spiritual beliefs may be, are necessary in order to achieve three important goals of healthcare as described by Koenig (2007, pp. 40-41): first, to understand religion's role in coping with illness or in causing stress; second, to gain a familiarity with patients' religious beliefs in relation to medical decision-making; and third, to identify spiritual needs of the patients, particularly those that could have an impact on health outcomes. Insufficient knowledge about spiritual assessment and uncertainty with what to do with information obtained through spiritual assessment have been previously identified as barriers to spiritual assessment in genetic counseling (Reis et al. 2007). Incorporating training in spiritual assessment as part of genetic counseling graduate program curricula and offering continuing education opportunities may be ways to improve obtaining and applying relevant R/S information. In addition, including a space for patient-reported religious affiliation on a genetic counseling intake form can provide both a tangible reference of the patient's religious or spiritual background and a tactful way for a counselor to reference the form and segue into an inquiry about faith in coping or faith in decision making. Alternatively, the addition of a specific question on the genetic counseling intake form to prompt patients to think about

their faith (or lack thereof), such as "Is your religion/faith something you use to make decisions in pregnancy? If so, in what way?" or the use of a portion of the HOPE tool such as "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?" may be considered (Anandarajah & Hight 2001; Reis et al. 2007). Finally, asking about a patient's religious affiliation or use of faith/religion in making important life decisions could also be included while obtaining a pedigree, as asking about this information on both the maternal and paternal sides of the family could provide a helpful framework for discussion.

The presence of 29% of the study participants being in high spiritual struggle as indicated by their NRC scores indicates that some women in high-risk pregnancy situations have spiritual doubts. While recognizing potentially harmful coping reactions is appropriate for genetic counselors, they can only be expected to address these reactions within the scope of their training and practice. Therefore, a referral to hospital chaplaincy or area religious leaders may be appropriate for those in spiritual struggle since exploring these issues from a theological perspective outside of their direct relation to the pregnancy is not within the genetic counseling scope. Thus, genetic counselors would be wise to establish good working relationships with the chaplains at their institution, and be ready to co-counsel or make referrals as appropriate (Lemons et al. 2013).

Research Recommendations

Further research in a more geographically and religiously diverse sample is indicated to assess whether the results from this study are truly representative of the desires of patients nationwide. As this study did not have a large sample of patients whose ultrasounds revealed fetal abnormalities, additional research in such a population may be helpful to determine if such indications instill different levels of positive or negative religious coping, as well as to ascertain differences in the extent of spiritual exploration by their genetic counselors. Assessing levels of R/S in participating genetic counselors could provide insight into whether a relationship exists between counseling behaviors and the levels of R/S of

the counselors. Finally, the development of a standardized spiritual assessment tool or intake question specific to prenatal genetic counseling may be helpful to identify the spiritual needs of patients in the absence of overt clues.

APPENDIX A – PATIENT LETTER OF INVITATION

Study on Religion & Spirituality in the Prenatal Genetic Counseling Session

What will the study involve? The study will involve a short survey that will be given after your genetic counseling session. It should take about 10 minutes to complete.

Why have you been asked to take part? You have been asked because you have a genetic counseling appointment today.

What about my religion/spiritual beliefs will you ask me questions about? You will be asked questions about whether you would like a genetic counselor to talk about your faith or spirituality during a genetic counseling appointment and whether it is an important part of your pregnancy.

Do you have to take part? You do not have to take part in the study. Participation is voluntary and you have the option of withdrawing your participation at any time. We do not keep any identifying information that will link you to the survey, so it is anonymous. Choosing not to participate in the study will not affect your care in any way.

What will happen to the information that you give? The data will be kept confidential for the duration of the study. After the study is completed, the data will be retained for one year and then destroyed.

What will happen to the results? The results will be used to generate data for a Master of Science thesis research project by a genetic counseling student. The thesis may be read by future students at University of Texas Health Science Center at Houston. The study may be published in a research journal or presented at a scientific meeting.

What are the possible advantages and disadvantages of taking part? There is no personal advantage to your taking part in the study. Results will be used to help genetic counselors and clinicians provide more personalized care for individuals receiving genetic counseling. Possible disadvantages may include anxiety or stress when thinking about family or pregnancy outcomes.

Any further questions? If you need any further information, you can contact the study investigators by email or phone:

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If you agree to take part in the study, please continue and complete the survey. By turning in the survey, you are agreeing to let the researchers use your answers.

APPENDIX B – PATIENT SURVEY

Part I: Demographics

1. What is your age? _____

2. What is the highest level of education you have completed?
   - o Never attended high school
   - o Some high school
   - o High school/GED
   - o Some college or 2 year/associates degree
   - o 4-year degree (BA, BS)
   - o Graduate or Professional degree (MS, MBA, PhD, MD, JD)

3. What is your current relationship status?
   - i. Single
   - ii. In a relationship
   - iii. Married
   - iv. Divorced
   - v. Widowed
   - vi. Other: _____

4. What is your religious affiliation?
   - ☐ Agnostic
   - ☐ Atheist
   - ☐ Baptist
   - ☐ Buddhist
   - ☐ Christian Science
   - ☐ Christian - other
   - ☐ Church of Christ
   - ☐ Church of Jesus Christ of Latter-Day Saints (Mormon)
   - ☐ Eastern Orthodox
   - ☐ Episcopalian/Anglican
   - ☐ Hindu
   - ☐ Jehovah's Witnesses

- ☐ Jewish
- ☐ Lutheran
- ☐ Methodist
- ☐ Muslim
- ☐ Pentecostal/Charismatic
- ☐ Presbyterian
- ☐ Roman Catholic
- ☐ Other: _____

5. With which race/ethnicity do you most identify?
    a. White, non-Hispanic
    b. Hispanic
    c. African-American
    d. Asian/Pacific Islander
    e. Native American
    f. Other: _____

Part II: Brief RCope

The following items deal with ways you coped/are coping with the possibility of undesired outcomes in pregnancy. There are many ways to try to deal with problems. These items ask what you did/do to cope with this negative event. Obviously different people deal with things in different ways, but we are interested in how you tried to deal with it. Each item says something about a particular way of coping. We want to know to what extent you did what the item says. *How much or how frequently*. Don't answer on the basis of what worked/is working or not – just whether or not you did or are doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can. Circle the answer that best applies to you.

1- Not at all
2- Somewhat
3- Quite a bit
4- A great deal

		None	Little	Medium	A lot
1.	Looked for a stronger connection with God.	1	2	3	4
2.	Sought God's love and care.	1	2	3	4
3.	Sought help from God in letting go of my anger.	1	2	3	4
4.	Tried to put my plans into action together with God.	1	2	3	4
5.	Tried to see how God might be trying to strengthen me in this situation.	1	2	3	4
6.	Asked forgiveness for my sins.	1	2	3	4
7.	Focused on religion to stop worrying about my problems.	1	2	3	4
8.	Wondered whether God had abandoned me.	1	2	3	4
9.	Felt punished by God for my lack of devotion.	1	2	3	4
10.	Wondered what I did for God to punish me.	1	2	3	4
11.	Questioned God's love for me.	1	2	3	4
12.	Wondered whether my church had abandoned me.	1	2	3	4
13.	Decided the devil made this happen.	1	2	3	4
14.	Questioned the power of God.	1	2	3	4

Part III: Genetic Counseling & Religion/Spirituality

Please indicate the feeling that describes your response to each statement below.		Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
1.	My religion or faith is an important part of my life.	1	2	3	4	5
2.	I look to my religion/faith for help in understanding and dealing with stressors.	1	2	3	4	5
3.	I use my faith to make decisions in my pregnancy.	1	2	3	4	5
4.	I would like to talk about my faith in the genetic counseling session.	1	2	3	4	5
5.	I am comfortable with sharing my faith and the way my faith influences my life and/or decision-making in pregnancy.	1	2	3	4	5
6.	The genetic counselor recognized my faith and the way that it affects my life, family, and pregnancy.	1	2	3	4	5
7.	I am happy with the way the genetic counselor addressed my faith and the way that it relates to my pregnancy/current situation.	1	2	3	4	5
8.	I would have liked the genetic counselor to pray with me in the session.	1	2	3	4	5
9.	I would have liked the genetic counselor to explore Scripture or other holy texts with me in the session.	1	2	3	4	5
10.	I would like it if I was given reference materials or spiritual resources to explore outside of the genetic counseling session.	1	2	3	4	5
11.	I would like it if the genetic counselor shared her own faith background or faith experience.	1	2	3	4	5
12.	What the genetic counselor and I talked about met my spiritual needs for this appointment.	1	2	3	4	5

Any additional comments:_____

_____

_____

_____

_____

_____

APPENDIX C – GENETIC COUNSELOR SURVEY

Study Questionnaire – Genetic Counselor:

1. What was this session's indication? (Circle all that apply and provide details as warranted)

AMA	+ FTS DS	+ FTS t18	+ Quad DS	+ Quad t18	+Quad NTD
Follow-up	+NIPT DS	+NIPT 18/13	+NIPT X/Y	Recurrent SAB	Hx infertility/CCS

Ultrasound abnormality:

_____

Prior child hereditary condition:_____

Carrier of recessive condition:

_____

Other:

_____

Additional details:

_____

2. Gravida _____ Para_____

3. On a scale of 1-5, how important did you feel religiosity/spirituality was to the patient?

1	2	3	4	5
Not at all important	Not very important	Uncertain	Moderately important	Absolutely essential

4. Please indicate any spiritual language that the patient used throughout the session (select all that apply).
   - ☐ Allah
   - ☐ Believe/belief
   - ☐ Christian
   - ☐ Church/Mass
   - ☐ Blessed/blessing
   - ☐ Destiny/fate
   - ☐ Faith
   - ☐ Gift from God

- God
- God's hands
- God's will
- Heaven
- Hell
- Holy
- Hope
- Imam/Scholar
- Jesus/Christ
- Karma
- Meditate
- Miracle
- Mosque
- Pastor/Priest
- Pray/praying for
- Rabbi
- Religion/religious
- Sacred
- Sin
- Soul
- Spirit/spiritual
- Synagogue/Temple
- Trust
- Other: _____

5. Additional comments: _____

_____

_____

_____

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