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“I Didn’t Know It Existed Before You Called”: Protestant Clergy Experience, Education and Perceptions Regarding Genetics

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Abstract

Despite the intrinsic role religious/spiritual (hereafter, R/S) beliefs have in patient clinical decision-making and crisis coping, there is little research exploring the relationship that exists between clergy (professionals who provide R/S counsel and guidance) and genetic counseling patients. This qualitative, exploratory study was designed to explore Protestant clergy ($N=8$) perceptions of and experience with genetics-related issues. Data analysis revealed that a wide range of R/S perceptions regarding genetics-related issues exist within Protestantism, Protestant clergy have a basic understanding of genetic testing and conditions, and while directive counseling is inherent to Protestant clergy counseling, there appears to exist two opposing styles: unbiased and biased. Based on this information, there are two main implications for genetic counseling clinical practice. First, R/S assessments need to be increasingly implemented into genetic counseling sessions, so that the psychosocial needs of patients with specific R/S beliefs can be identified and addressed. An increase in R/S assessments may be accomplished by increased exposure in genetic counselor training, continuing education opportunities, and by establishing relationships with board-certified, professional chaplains. Second, genetic counselors can influence the genetic education and experience of clergy by raising awareness within their own R/S assemblies. Doing so can also serve to further educate genetic counselors in the R/S beliefs of their own traditions, thus increasing sensitivity, empathy and the quality of care provided.

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Keywords

Genetic counseling; Genetics; Clergy; Protestant; Religious beliefs; Spiritual beliefs

Introduction

While religious/spiritual (hereafter, R/S) beliefs have an intrinsic role in patient clinical decision-making and crisis coping, there is little research that explores how specific R/S beliefs influence the unique clinical decision-making process and specific crisis situations that are involved with genetics-related issues. This information deficit is significant when considering that approximately 90 % of the United States identifies with a religion or belief in a higher power (Kosmin and Keysar 2009); clinically speaking, "...patients professing a belief in the divine are likely to seek comfort, guidance and equilibrium from their faith" (Anderson 2009, p 52). Having a better understanding of how specific R/S beliefs influence perceptions of genetics-related issues can help increase counselor sensitivity to patients' specific psychosocial needs. With this increase in sensitivity, counselors can "listen and respond more empathetically to clients' emotions and concerns" (Grubs and Piantanida 2010, p. 102).

Unfortunately, the available studies that aim at increasing genetic counselor sensitivity to patient R/S issues only focus on one of two major themes. The first theme surrounds clergy perceptions of pregnancy termination in light of either genetic conditions or genetic testing (Anderson 2009; Stuck et al. 2001; White 2000). For example, Stuck et al. (2001) found that the more lethal a genetic condition was perceived, the less likely Lutheran pastors were to be against termination. While these results provide valuable insight into how Lutheran clergy perceive prenatal genetic issues as they relate to termination, there is no representation of other faith traditions. Anderson (2009) investigated a wider representation of religious traditions and their individual perspectives on prenatal genetic counseling issues, such as termination, pregnancy loss and neonatal illness/death. While these studies provide important information that is integral to better understanding patient R/S beliefs, none address clergy perceptions of genetics beyond prenatal care and are therefore minimally applicable to other genetics-related issues.¹

The second theme focuses on how the R/S beliefs of genetic counselors impact their clinical counseling practice (Bartlett and Johnson 2009; Cragun et al. 2009; Galanter et al. 2008; Pirzadeh et al 2007; Reis et al. 2007; Salamone 2002). Salamone (2002) surveyed genetic counselors and found that 68 % either agreed or strongly agreed that R/S is important to discuss with patients, but more than 70 % of counselors rarely or never assessed patient R/S. Reis et al. (2007) evaluated genetic counselors' practices of spiritual assessment and found that genetic counselors most often address patient R/S based on the perceived relevance of and comfort with performing a R/S assessment, which was determined to be either when a patient initiated the conversation, when discussing termination, or when end-of-life issues were involved. This is significant in demonstrating that genetic counselors have a bias

¹Genetic conditions, genetic testing, genetic medical management, advances in genetic technology and genetic education

towards addressing the R/S of a patient only when it is relevant to the counselor, implicating a significant discomfort among genetic counselors to explore R/S concerns of patients that fall outside of the categories of perceived relevance (i.e., termination, end-of-life issues, and patient-initiated conversation).

While many studies explore the various relationships that exist between R/S beliefs and genetics-related issues, (Anderson 2009; Baumiller 1988; Churchill 2009; Evans and Hudson 2007; Lebel 1978; White 2009), there is little published information that specifically explores how the R/S beliefs of clergy as individuals influence their perception of genetics-related issues. One of the only studies to specifically explore clergy perceptions (Bartlett and Johnson 2009) discusses both clinician and clergy perceptions of religion and genetics by comparing how the two professions perceive the relationship between science and religion (e.g., complementary or oppositional) and how this perception affects patient care. However, since Bartlett and Johnson do not explore the express beliefs of the clergy regarding genetics-related issues, minimal information can be learned about how clergy beliefs affect their perceptions.

Most of the research concerning clergy and genetics either highlights the need for more genetics education within the clergy or ethical considerations through the lens of Catholicism. One of the earliest publications is a workbook by Baumiller (1988), a Catholic priest and geneticist at Georgetown University. This workbook contains a brief section on how and why clergy should become involved in genetic support groups and clergy guidelines on how to spiritually care for the intellectually disabled and those who are carriers for a genetic disease (e.g., families of Jewish descent). Even at this early stage in the field of genetics and genetic counseling, Baumiller appreciated that, “The clergy, in addition to (offering) deep concern and strong faith, must become aware of the complexities of inherited disorders and the effects not only on the individual patient, but on whole families, sometimes over several generations”(National Digest, p. 10).

Mertens et al. (1986) surveyed the human genetics/bioethical needs of Indiana clergy, and came to a similar conclusion, saying, “...clergy must be aware of advances in medical genetics and reproductive technology which may ultimately create moral and ethical issues for members of their congregations” (p. 52). In spite of the previous studies that emphasize the importance of clergy genetics education, a study years later by Stone (1999) revealed that, “The pastoral care and counseling profession has not yet entered the [genetic counseling] field to any extent” (p.173), and, much like his predecessors, Stone believed that this integration needs to happen.

The call for more substantial genetics education among clergy and increased involvement in clergy counseling about genetics-related issues has been a consistent theme over the past four decades, and needs to be re-evaluated. The limited number of studies concerning how the R/S beliefs of clergy influence their perception of genetics-related issues, and a standing need to re-evaluate the genetics educational deficits of clergy, exemplify the necessity for a closer evaluation so that any knowledge deficits can be identified and effectively addressed.

Purpose of the Present Study

A limited amount of research has investigated how R/S beliefs are used to interpret and influence perceptions of genetics-related issues. The data generated from such research may impact the quality of care individuals with genetic concerns receive. The purpose of this study was to explore Protestant² clergy experience and knowledge regarding genetics-related issues, which includes genetic conditions and genetic counseling. There were two major research questions: 1) What are Protestant clergy perceptions of genetics-related issues, and 2) What are their experiences with and knowledge of genetics-related issues? Since Protestant denominations comprise the largest religious group in the U.S. (Kosmin and Keysar 2009), clergy from Protestant denominations were targeted to represent a range of viewpoints within Christianity in the United States.

Methods

Participants

This study was approved by the institutional review boards of both the academic and clinical settings where it was conducted. In order to best identify how R/S beliefs are being used to interpret and perceive genetics-related issues, participants were randomly selected from a list of 413 congregations in the Ohio/Kentucky/Greater Cincinnati area, which was compiled as the result of a separate study in 2008 (Szaflarski 2008). Of the 413 congregations, 295 were categorized as belonging to one of eighteen Protestant denominations.³ Random selection was accomplished by assigning each Protestant denomination a number, 1 through 18. An online random number generator was used to establish the order in which the first author would contact each denomination. Once a denominational call order was established, congregations within each denomination were assigned a number (using the same online random number generator), which established the order each congregation within that denomination would be contacted by the first author. Clergy were contacted by telephone to participate. Based on the authors' experience within the clerical community, and prior interviews with clergy, only senior/lead clergy were invited to participate as they were the most likely to have experience interacting with and counseling adults or couples in the congregation.

When clergy could not be contacted directly, either a voicemail was left on an answering machine or a message was left with an administrative assistant. After leaving a message for clergy of one denomination, the next denomination on the call list would be contacted by telephone. The congregation affiliated with the denomination next in the call list was then contacted. This method was used until theoretical saturation was reached. Theoretical saturation was determined to be the point at which gathering more data about the emerging themes does not yield any additional insight (Charmaz 2006).

²Protestant is defined as any Christian not of a Catholic or Eastern Church. Clergy from Catholic, Mormon and Jehovah's Witnesses churches were excluded due to fundamental dogmatic and doctrinal differences not in the scope of this study.

³African Methodist Evangelical, Assembly of God, Baptist, Church of Christ, Church of God, Church of God In Christ, Disciples of Christ, Evangelical Lutheran Church of America (ELCA), Episcopal, Friends Meeting, Mennonite, Methodist, Nazarene, Non-Denominational, Orthodox, Pentecostal, Presbyterian and Wesleyan

When clergy expressed interest in participation, a study summary document was sent by e-mail, outlining the details of the research. This summary also served as the informed consent document. Once participants read and acknowledged comprehension of the study summary, either through a phone call or e-mail to the first author, the location, date and time of the interview was established. Once established, participants were e-mailed a demographic information form to complete, and this form was returned to the first author either by e-mail or in-person during the interview.

Instrumentation

Demographic form—A demographic form(see Appendix) was developed to obtain information about participants' gender, race/ethnicity, age, parental status, highest level of education, time elapsed since receiving highest level of education, number of continuing education conferences/courses attended each year, and any educational experience with genetic issues.

Interview guide—Eighteen main interview questions (see Appendix) were developed to help guide the conversation with each participant. The interview questions were developed using information gathered from a variety of sources, including two texts specific to theology and genetics-related issues (Cole-Turner and Waters 1996; Swinton & Brock 2007) and the professional knowledge of the authors of this study. After the interview guide was drafted, it was piloted with a board-certified hospital chaplain at the clinical institution where this study was developed. This pilot study led to minor changes in the wording of a few questions, so that either the intent of the question was more understandable for a participant or the question was better able to relay the intent of the authors to the participants.

Procedures

Interviews were conducted by the first author and took place in-person, typically in the participant's office. On two occasions, interviews took place at a public site chosen by the participant as being an acceptable and conducive environment for conversation. Interviews followed an open-ended, semi-structured interview guide. Transcripts were reviewed after the first three interviews were completed. Potential revisions to the interview questions were discussed and, in some cases, implemented based on the content of responses (Charmaz 2006). Interviews were audio-recorded using two recorders to ensure the capture of data.

Data Analysis

Audio-recordings of the interviews were transcribed and verified for accuracy by the first author, with all identifying information being deleted in the process. The first and senior authors concurrently analyzed interviews to counteract potential bias and to minimize the need for iterative revisions to the semi-structured interview guide based upon the emergence or non-occurrence of anticipated themes. The interview transcripts were coded by the first and senior authors into individual meaning units, or nodes; similar nodes were grouped into categories and then into conceptual themes. Concurrent with data collection and analysis, the first and senior authors recorded memos based on personal thoughts and feelings evoked through data collection and analysis, which would later aid in data interpretation (Charmaz

2006; Grosseohme et al 2011, 2010; Ragsdale 2008; Ragsdale et al 2009). Data analysis and management was done using NVIVO 9.0, which is a specific type of computer software available for purchase by anyone through the company website. NVIVO 9.0 allows users to arrange and classify qualitative data as categories and themes emerge. While this freedom to arrange and categorize information enables researchers to explore relationships in the information in a variety of ways, the relationships observed are user-dependent. For this reason, the data in this study was analyzed by both the first and senior authors so as to minimize any potential user-dependent biases.

Results

Out of 295 congregations, the clergy of over 70 congregations were either directly contacted, had a message left on a workplace voicemail or a message given to an administrative assistant. Of the 70 congregations contacted, the first author spoke directly with a member of the clergy from eight of the congregations, and these eight individuals comprise the sample in this study. There were seven males and 1 female with a median age of 55–60 years. All participants had earned at least a Bachelor's degree, with most ($n=5$) having earned a Master's level education. More than 15 years had passed since receiving any type of genetics education for all but one participant, who had recently graduated with a Bachelor's degree. Each participant's church was located in an urban setting and had a congregation size between 100 and 300 people. All but two participants stated that they had previously had some form of genetics education. Complete demographic information is provided in Table 1.

There were 656 initial nodes extracted from the interview transcripts that were condensed into several representative categories from which three themes emerged: experience with genetics-related issues, perceptions of genetics-related issues, and counseling techniques. It is important to note that when reading the results, when a participant refers to “man” or “men,” this is interchangeable with the more inclusive terms “people” or “humanity.”

Theme 1: Experience with Genetics-Related Issues

Genetic Counseling—There were two distinct levels of experience with genetic counseling for the participants: those who had not heard of genetic counseling prior to the study, and those who had heard of it. Five participants disclosed that they had not heard of genetic counseling prior to the study, one stating, “I didn't know it existed before you called,” while the remaining three stated that they knew genetic counseling existed, but could not clearly communicate what genetic counseling is or why someone would seek genetic counseling. For example, one participant said, “I know a little about it, I know it exists...I don't know a whole lot more than that.” Of those who knew that genetic counseling existed, none could definitively say they knew of anyone who had received genetic counseling.

Participants were also asked to describe their perceptions of the reasons someone might receive genetic counseling. Reasons included: a family history of breast cancer (e.g., “Genetic counseling particularly takes place with women with breast cancer”); couples wanting to know if they should have children based on their genetics (e.g., “Genetic

counseling relates to a couple wanting to have a baby and wondering if genetics were an issue”); couples who are seeking in-vitro fertilization (e.g., “There was a couple in our congregation that had IVF...but I’m sure they underwent some genetic counseling; so I’m familiar that it exists”); and anyone in a particular situation who needs their genes and heredity explained to them, (e.g., “[Genetic] counseling...tries to one, get at the genetic root of a particular problem; two, explains to an individual the background or the reason for a particular situation based on their heredity”).

Genetic Testing—Only two participants reported experience counseling someone about genetic testing. The two circumstances included knowing a woman who had “problems with her baby,” and being asked to help individuals obtain paternity tests. The remaining six clergy did not have any experience with genetic testing. Participants were also asked if they could provide examples of their understanding regarding why people would seek genetic testing. The most frequently cited reason was for homosexuality ($n=3$). Other reasons included cloning ($n=1$) and sickle cell anemia ($n=1$). The remaining participants ($n=3$) did not provide examples because they did not know of any, as one participant stated by saying, “I don’t know what type of situations people consider genetic testing.”

Genetic Conditions—Seven of the eight participants had no direct experience, which would include any counseling or discussion about a genetic condition, with congregants. The remaining individual had personal experience with a congregant who had a clinical diagnosis of Huntington’s disease. Although unable to recollect specific information discussed, this participant admitted that genetic testing should have been a part of their conversation but was not.

Genetic Education—A misunderstanding of genetics became apparent throughout the interviews. For instance, the clergy were asked to describe hypothetical situations in which they would provide genetic information to congregants as factual. Based on the examples they gave, it was apparent that the information was often inaccurate. For example, one participant hypothetically counseling an African American couple concerned about having a child with sickle cell anemia stated their risk of having a child with the condition as being 1 in 440,000, indicating there was “no cause for concern” on their parts. However, approximately 1 in 500 African Americans have sickle cell anemia, with a carrier frequency of 1 in 12 among the African American population (National and Lung and Blood Institute 2011). This participant went on to say that even if they had a child with sickle cell anemia, they can have three more kids without the condition because “that’s the odds of the disease.” Another participant, who reported gathering scientific information from the online publications of Albert Moehler (president of Southern Baptist Theological Seminary in Louisville, Kentucky), placed alcoholism and homosexuality side-by-side as conditions that are genetically based, saying, “The modern theory is that alcoholism [and] homosexuality is [sic] genetically based.” While discussing the death of children who had a genetic condition, another participant quoted that 80 % of marriages would end in divorce, while current statistics actually support that the percentage is closer to 12 % (The Compassionate Friends 2006).

Data support that participants had limited formal genetics education (see Table 2). Two participants had not received any formal training, while another two participants had taken bioethics courses where genetics was briefly discussed. One of these two participants disclosed in the demographic survey that in the bioethics course taken, “[The] professor talked about eugenics and dangers of gene selection, mostly negative.” The other participant did not elaborate on what was discussed in the bioethics course, but did mention completing it in 1978. Several participants disclosed how they educated themselves on current scientific advances and technology, which included genetics, by “watching TV a lot,” watching CNN and Discovery channels, and subscribing to scientific magazines such as Smithsonian and Discovery.

Genetics in the Church—Half of the clergy indicated they have never had anyone in their congregation ask for their guidance or advice concerning genetics-related issues, or as one participant indicated, “No one has told me.” Another participant even asked, “How do you make the topic come up?” Of those who mentioned having discussed a genetic issue with their congregants, two could not explicitly state what was discussed; for instance, one person said, “I can’t think of a specific instance, but I know that there have been conversations about it.” The experience of the remaining two participants was either isolated to environmental exposures (e.g., “The only times I have had experience... women had X-rays before they knew they were pregnant”) or discussing a congregant’s diagnosis of Huntington’s disease approximately 12 to 14 years ago.

None of the participants had ever given a sermon on any genetics-related issue; however, three stated they only preach on a specific topic when it is something that has come up within the congregation or when someone specifically requests the topic to be discussed. As one individual stated, “[Genetics] is not really a topic of discussion, so I guess people look at it as a non-issue, really.” No other clergy provided a reason for why they had not given a sermon on any genetics-related issue.

Theme 2: Perception of Genetics-Related Issues

Throughout the interview process, the participants were asked how they viewed or felt about specific genetics-related issues, such as referring congregants to genetic counselors and the relationship they perceive to exist between God and genetics. Since they were free to answer how they best saw fit, participants also expressed their perceptions of genetics-related issues which they were not directly asked about, such as homosexuality and the cause of genetic conditions.

Genetic Conditions—When asked what they thought about when they heard “genetic condition,” two clergy said they tended to think about DNA or genetic material that God had given to someone (e.g., “I would think of something that is part of anybody’s biological make-up...whatever their DNA is that was given to them in creation” and “Make-up, how you are designed...God”). Three participants thought of heredity (e.g., “Disease... Inheritance, generations”; “Somebody’s heredity, their DNA”; and “Genetic conditions can be any number of diseases or disabilities that are traced back through families and can go back 30 and 40 thousand years...”). Conditions clergy considered to be genetic include:

alcoholism, Alzheimer's disease, breast cancer, Down syndrome, heart disease, homosexuality, Huntington disease, and sickle cell anemia.

Genetic Testing—Every participant perceived genetic testing as a means for detecting genetic abnormalities and genetic susceptibilities that cause certain conditions or health problems. For instance, “They (scientists) are trying to find out what gene caused a particular problem”; “[genetic testing is] probing someone's genetic make-up for any number of reasons, to detect abnormalities”; and “People are doing testing to see what tendencies they might have, what needs they might have.” Only one person perceived genetic testing to be used to gather information about the future, saying “...I guess I think of parents, babies, but also adults curious about their future...”

When clergy discussed the purposes that might lead someone to undergo genetic testing, their responses fell into two categories: to prepare emotionally for an unexpected outcome, and to make a decision whether or not to terminate a pregnancy based on the genetic testing results. When clergy described undergoing genetic testing for preparation purposes, two participants were in favor, stating, “In testing for Down syndrome... seems more like ... you want to know how you can better prepare yourself to take care of this child...”; and “Sometimes it's better to know bad news than be wondering about it...it's better to find out and then you can adjust to it.” When clergy described undergoing genetic testing to make decisions about terminating a pregnancy, six of the participants were against genetic testing on the basis that people with Protestant R/S beliefs should trust God instead of trying to control their lives so much. For example, “...you get what you get, and for people of faith it seems to me that our job is to receive the gift given and trust that that's okay, rather than to come into situations with predetermined notions about the way it ought to be, which I think is all a part of our desire to control everything”; “All of us have different issues we have to bear in our life and we should expect that. We should expect to find His strength to get us through it”; and “...we are selfish because we are self seeking when we pick what child we want and what child we don't want...choosing what fits our lifestyle rather than what fits His plan.”

Clergy's Role in Counseling about Genetics-Related Issues—The majority of participants ($n=5$) felt that it was their role to provide a R/S framework for understanding genetics-related issues. For example, “I think my role in this as a [pastor] is to always be pointing people to God...Let's make sure you're reflecting on it in that framework”; one of these participants felt that it was the role of the clergy to help someone live for today, “You can't be afraid of tomorrow because it's going to impact how you live today...my focus is going to be to help the person to live for today.” The remaining three participants held differing views on the role of clergy in counseling about genetics-related issues. One stated that genetics-related issues may impact interpersonal relationships, and therefore clergy should help people think this through, as well, “...helping them think through the implications of the decision and how this affects not only themselves but how it affects their relationships...” Another felt that it was the role of the clergy to let people figure it out their own, saying “God gave us the capacity to figure these things out...I would just...let them figure things out on their own and ask some questions about how they were handling the

stress...” The third participant expressly stated that the role of clergy was to provide a safe place for congregants, “This [counseling by clergy] would be a safe place for people if they needed it...no matter what their choice was, let’s stand by them. That’s what God does with us.”

Relationship between Genetics and the Church—Participants were asked how they felt the Church has responded to the advances in genetics, if at all, and to express their thoughts concerning this issue. All but two individuals felt there were ways that the Church could be responding more effectively. For example, one participant commented that the Church should develop some type of a curriculum to learn more about genetic advances and the related issues, “It would be wonderful if there was some kind of curriculum to be used in a congregation... there’s an ongoing need for continuing education with clergy.” Another remarked that congregants who have a scientific profession need to take some responsibility in educating the rest of the Church, “I don’t think that there’s enough science people in church that take their profession seriously enough to want to dialogue with the rest of the church...it’s the lay person’s position to say we need to talk about this in our church...”

Of the two who stated that they felt the Church was “where it should be,” one felt the Church should not be exerting energy in the area of genetics, but in other areas, “...I don’t know that the Church needs to spend its energies in that area whereas other energies need to be in other areas,” and the other felt that more involvement of the Church would be necessary only if designer children became more of a concern, “I think we [the Church] are where we should be, unless science moves towards encouraging our people to do things we think are contrary to scripture...we shouldn’t selectively try to come up with this super person and super genes...” Two participants mentioned there are some R/S traditions that purposely avoid responding to advances in genetics, saying “...some religious traditions are just very anti-intellectual, and they just don’t want to go there, and that God will solve all problems...” and “I think the Church needs to open up...God has given us minds to be used, and to try and love God with our intelligence... [to] build up human life and human community.”

Referral to a Genetic Counselor—When asked how they felt about referring congregants to a genetic counselor, every participant indicated they would feel comfortable doing so, with four participants explaining that as clergy, they are not trained to counsel about such a specific topic. For example, “Yes, [I would refer]...I am open to the conversation but wouldn’t claim any kind of expertise”; “Yes...I know my limitations...You want the person with the expertise to deal with it”; “I am not a qualified counselor in this area, therefore this may be what I think this is, what the Word says, but you may want to consult and give them a reference to someone who would be more qualified than I”; and “Yeah, I would... We’re not trained to be counselors or therapists. There are people who are trained to deal with things.” Only one person stated they would refer to a genetic counselor on a case-by-case basis, commenting that it, “Depend[s] on what their intent is. If they were looking for genetic counseling to determine whether or not to consider pregnancy, then no. If they were looking for genetic counseling to determine whether or not they could conceive, then yes.”

Relationship between God and Genetics—Each participant stated that God created human beings in His image, and therefore God created genetics. However, there was a wide spectrum of interpretation as to what this means for the relationship that exists between God and genetics. For example, one participant said the fact that God created human beings is the reason why he does not believe in evolution, “First of all I would clarify that I believe God created man in his own image, so I discount any form of evolution. As a result of that, God is the creator of genetics.” Using the same reasoning, that God created man in His image and, therefore genetics, another participant supported his belief in a form of evolution by saying, “What makes us human is putting all the genes together and obviously the genes are all there for a reason. It’s a part of Creation, and that it has been a way God, over time, has created us; I do not take a literal view of creation in 7 days.” One participant took a different approach to the same belief of God creating human beings, in regards to where the study of genetics may lead humanity, saying, “Ultimately, we might find out we didn’t help mankind, but that we’ve damaged it horribly because we tried to make too many changes... We’ve got to trust God...we are God’s creation, and God is not going to let us destroy ourselves because He loves us.”

Cause of Genetic Conditions—While not directly questioned about the cause of genetic conditions, all of the participants stated what they understood to be the cause of genetic conditions. Three referenced the Fall of Man (when Adam and Eve ate the fruit from the Tree of Knowledge and were subsequently removed from the Garden of Eden) as the cause of genetic conditions. For instance, one participant said, “Now, the Fall of Man did affect [DNA]. Sin has affected [DNA], so that’s why you have disease...Adam and Eve had pure genes; today we have defective genes...It’s because we live in a Fallen world we have [genetic conditions].” The other two participants stated that, “We have to realize that it is the Fall of Man that causes us to live in a Fallen world that has all these diseases and sickness...” and “It (the presence of genetic conditions) again goes back to the Fall. They (genetic conditions) not part of God’s original creation...We live in a Fallen world and they (genetic conditions) just happen...”

Three participants expressed that genetic conditions are caused because they are God’s will, and as such, some form of good will come out of people having genetic conditions. For example, “...God is taking everything and works it for His good and our good...”; “What he does is for His glory, the Kingdom’s glory and our benefit, eternal benefit, not immediate necessarily, but eternal benefit”; and “What I see here is that even when man thinks this is a terrible thing, that God is in control, that God has made us specifically different for His purposes in our life...”

Three additional clergy provided specific examples of the type of good that can come from people having genetic conditions by saying, “I don’t know if I entirely subscribe to this, but you know, God puts those who we need to care for, who are developmentally disabled, who are incapable of caring for themselves, as a way for us to prove our humanity, to express our humanity”; “... when we find people with disorders and diseases, that’s our opportunity to love and care, to go out of our way to help other people”; and “This [genetic condition] may be God’s way to getting this particular child to heaven, by say withholding mental abilities, physical abilities. God may have loved him so much, knowing that he may have chosen

wrong in life, God has allowed him to be this way. Each situation, each person, you have to take into consideration.”

Homosexuality—While none of the clergy were asked about their views regarding the genetics of homosexuality, three participants expressed an opinion on the subject. One discussed the discovery of a “gay gene,” stating that, “I think where genetic counseling and testing could hit a real brick wall is if they ever found a gene that could cause sexuality: a gay gene. Trust me. The gay community will come out against abortion by the boat loads, and they’ll come out against genetic testing because the first thing most families would do is test for and want to eliminate that gene.” The other two participants discussed their views of whether homosexuality was genetic or not by saying, “I feel homosexuality is a sin problem, not a genetic problem. We all have different sin problems. Could there be some genetic things that make men prone to those types of things? Probably...but it doesn’t mean that because I am born with these genes that I was predetermined to fall into that lifestyle” and “Homosexuality is not genetic. It’s a choice, it’s a behavior...God made Adam and Eve, not Adam and Steve...We have a tendency towards evil, that’s a moral issue, not a genetic issue.”

Healing—Two participants touched on the subject of healing, one expressing the belief that, “[God] heals by natural processes, by medicine...instantaneously...He knows the genetic makeup if that’s causing the problem...He can heal it, and He does on occasion...He can let the recessive dominate when it should.” The other participant expressed the opposite belief by saying that, “...can there be healing and changing? Yes...but I don’t claim to know about any ability to do that...In fact, I’m pretty sure it’s not possible. But, you know, anything is possible I guess if God’s working on it.”

Theme 3: Counseling Techniques

Throughout the interview process, participants were asked how they would respond to congregants seeking counsel regarding specific genetics-related issues. Clergy counseling techniques were determined based on these responses. While everyone provided responses that indicate a directive counseling approach, there was a clear difference in just how directive participants envisioned themselves being with congregants, either providing unbiased or biased directive counseling.

Unbiased Directive Counseling—For the purposes of this study, unbiased directive counseling refers to participants who expressed their desire to help congregants come to their own decisions grounded in biblically-based R/S information, as opposed to personal opinion. According to this definition, five of the eight clergy indicated they would provide unbiased directive counseling, as follows: “My role is to answer their questions in relation to scripture rather than personal opinion. If scripture is silent, I am silent”; “I’m not here to decide for them, but I am here to help them come to terms with their faith...”; “My role is just to share what I know [about the bible] and try and help the person understand like you’re trying to help me understand...”, “I’d...try to provide some kind of spiritual, religious, theological framework for understanding these questions...”; and “I think my job

as a [pastor] is really to help people to see where is God in this, but not pretend to be an expert.”

Biased Directive Counseling—For the purposes of this study, biased directive counseling refers to participants who expressed their desire to help congregants come to a decision based on their personal opinion of what is right and wrong due to their interpretation of the bible as it relates to R/S issues. Three of the eight clergy gave responses indicating they would provide biased directive counseling, saying, “I think it’s wrong to say that, ‘This world today, we don’t want to bring any children in the world.’ [I] would discourage that”; “If you have someone come in...give them their options and [help them] understand this is what’s going to take place and then go out and have a nice day...I’m just going to give you my opinion and that’s all I can do”; and “My response was...that the Lord knew when this child was conceived even though the doctors didn’t. He is the Giver of Life; we don’t have the option of being the takers of life.”

Discussion

Over the last 20 years, interest in analyzing the relationship between religion and genetics has gradually increased (Anderson 2009; Bartlett and Johnson 2009; Baumiller 1988; Churchill 2009; Mertens et al. 1986; Mills 2002). To a certain extent, clergy perceptions of a few genetics-related issues have been explored (Bartlett and Johnson 2009; Stuck et al. 2001). However, none of these studies have explored the direct experience clergy have, nor the explicit perceptions they maintain, regarding genetics-related issues. To the best of the authors’ knowledge, this is the first study that jointly explored Protestant clergy education, experience and perceptions regarding genetics-related issues.

It is no secret that even within a single denomination, let alone all of Protestantism, there exist disparate views on most doctrinal, if not certain dogmatic, issues (Anderson 2009; Cole-Turner and Waters 1996; Evans and Hudson 2007; Stuck et al. 2001). As seen in this study, genetics-related issues are not exempt from being a topic of deliberation within R/S groups. However predictable, one of the most noteworthy aspects of this study is learning just how wide the range of perceptions is amongst Protestant clergy. Even if participants appeared to have a similar perception, their interpretations of genetics-related issues could be the exact opposite of each other (e.g., all participants believed God created genetics, but some used this to support Creation, while another used it to support evolution). These results suggest genetic counselors and other genetics professionals would be well advised to not have predetermined notions of what a patient may believe solely because their demographic information labels them as belonging to a specific R/S group. If there is this much disparity in both perceptions and interpretations among Protestant clergy, there likely exists the same or an even wider range of perceptions within congregations.

Even though the Protestant clergy interviewed in this study reported a range of perceptions regarding genetics-related issues, one area of commonality was their provision of some form of directive counseling. While it may not be surprising to hear that these clergy do not provide nondirective counseling, it is important to highlight why this does not happen. At least as far as Protestant denominations are concerned, the act of seeking out the counsel and

support of clergy is indicative of a person searching for one of two things: spiritually and biblically based direction for decision-making, or atonement and/or forgiveness of a perceived sin. Therefore, due to the very nature of pastoral counseling, it is impossible for clergy to provide non-directional counseling. "In contrast to psychologically-integrated systems, Biblical counseling seeks to carefully discover those areas in which a Christian may be disobedient to the principles and commands of Scripture and to help him learn how to lovingly submit to God's will," reports the International Association of Biblical Counselors ("Counseling God's Way," 2010, para.1). Anyone who provides biblically-based counsel, such as clergy, are unable to provide non-directional counseling, because they have an absolute standard, the Bible, by which to measure their objectives and evaluate their counselee's lifestyle. This is very different from the non-directional counseling that genetic counselors are encouraged to provide, as there is no comparable absolute standard with which genetic counselors measure and evaluate a patient's lifestyle and decisions.

There appears, however, to be two very distinct types of directive counseling provided by clergy, unbiased and biased. On one end, some of the participants used unbiased directive counseling. These clergy expressed a desire for their congregants to make the best decisions for themselves and their families using biblically-based R/S information; they refrained from the use of personal opinion. For all practical purposes, this is not very different from nondirective genetic counseling. Apart from not having an absolute standard, genetic counselors impart scientifically-based information (as opposed to biblically-based information), so that patients can make the best decisions for themselves and their families; and genetic counselors refrain from the use of personal opinion.

On the other hand, some of the clergy participants used a more biased directive counseling technique. They viewed it within their scope of practice to interpret biblically-based R/S information for congregants, therefore providing their own opinion about what decisions congregants should or should not make. Some of these clergy expressed the purpose of children with intellectual disabilities is to give people a chance to be loving and caring, while other stated that without the disability, a person would have gone to Hell. This directive counseling technique is rather disconcerting. While not expressed by the participants of this study, but encountered by the authors, some biased directive counseling by clergy includes the view that children are born with genetic conditions as a way of punishing the parents for a past sin, or, if a woman has an abortion, she is going to Hell. These, and undoubtedly many more, are examples of the types of R/S perceptions genetic counselors need to be aware of and address when their patients hold R/S beliefs.

Not surprising, most Protestant clergy in this study had little or no experience or education regarding genetics-related issues. These results are similar to those of previous studies (Mertens et al. 1986; National Digest 1981; Stone 1999). However, information not explored in previous research is that even without much education or experience, the present participants seemed to have basic knowledge of what genetic conditions are and what purpose(s) genetic testing serves. While it is impossible to speculate on the basic understanding of these topics by clergy over the past 20 years, it may be hypothesized that most Protestant clergy today have a basic knowledge of genetic testing and conditions. Even more heartening, are the findings that even if clergy did not know what genetic counseling

was, most expressed a willingness to refer someone to a genetic counselor. Many of the participants acknowledged that as clergy, they are not the best people to be counseling someone about genetics-related issues.

While most Protestant clergy do not support pregnancy termination, except in unusual circumstances, (Pew Forum on Religion & Public Life, 2010), the responses in this study indicated a belief that genetics-related issues and decisions surrounding them should be left up to the patient and the genetics professional. Thus the findings of this study help to affirm prior claims that most clergy view their role in genetics-related issues as helping people make decisions within the framework of R/S beliefs (Baumiller 1988; Cole-Turner and Waters 1996; Swinton and Brock 2007). However, as this study elucidates, the differences in how the clergy perceived their counseling role lie in whether the help they offer is more unbiased or biased in nature.

Implications for Genetic Counselors

Genetic counselors can use the information derived from this study to enhance the quality of care they provide within their own practice. Having a better understanding of how clergy use R/S beliefs to interpret genetics-related issues can increase their sensitivity to the specific psychosocial needs a patient may have. Increased sensitivity may allow counselors to respond more empathetically to patient concerns and emotions. It is imperative that genetic counselors become more comfortable in assessing their patient's R/S needs. This is a crucial step in discovering whether a patient has any R/S beliefs or perceptions regarding genetics, such as the ones seen in this study. According to Reis et al. (2007), less than 9 % of genetic counselors performed an assessment in more than 50 % of their sessions that would allow patients to express R/S concerns. This may be explained by the finding that 60 % of the genetic counselors either did not know how to assess patient spirituality or did not know what to do with the information once given. Genetic counselors need to become much more comfortable performing a R/S assessment, as it is the most effective way to address patient R/S needs. More education and experience regarding R/S assessments are needed in genetic counseling programs and in continuing education opportunities to enhance counselor comfort and skills.

While no published data currently exist about genetic counselor—chaplain relationships, establishing a close working relationship with board-certified chaplains in the workplace may provide another valuable way to assist genetic counselors in successfully implementing R/S assessments with patients. Genetic counselors can not only engage in open dialogue with these specially trained clergy about how to best incorporate R/S assessments, but they also can offer the aid of a board-certified hospital chaplain to patients who may prefer a more anonymous conversation, rather than speaking with their own R/S leader. Offering the aid of chaplains is beneficial for patients unaffiliated with a congregation and who have no R/S leader with whom they can speak. Lastly, the findings of this study suggest that Protestant clergy are not being approached by congregants for counsel regarding genetics-related issues, although the reasons are not very clear. Perhaps some individuals are afraid to discuss potentially controversial issues with their clergy. Regardless of the reason, it is

important that genetic counselors become comfortable referring patients to chaplains, as patients may not seek R/S counsel on their own.

The results of this study also suggest Protestant clergy have limited genetics education. A considerable need for genetics education is obvious in that while most participants freely admitted to not being experts in genetics, some still found it within their scope of practice to provide congregants with genetic information, which was often inaccurate. Genetic counselors could make a tremendous impact on the experience and education of clergy who are called upon for counsel about genetics-related issues. Almost 40 % of genetic counselors indicated they attend a religious service at least once a month (Cragun et al. 2009), and about 47 % of genetic counselors reported regular attendance at a religious service was moderately to very important to them (Geller et al. 2009). Based on these data, the genetic counseling profession would benefit from counselors sharing their expertise with clergy from their own R/S affiliations. This is particularly due to the fact that educating R/S clergy could include genetic counselors making their services and resources known, which would better facilitate congregant referrals to genetic services. However, as one study participant stated, “I don’t think that there’s enough science people in church that take their profession seriously enough to want to dialogue with the rest of the church...it’s the lay person’s position to say we need to talk about this in our church...” These findings suggest it may be up to genetic counselors to initiate the conversation with their R/S leader. These conversations could occur in a variety of settings, including one-on-one, in the form of a small group or a more formal continuing education class for both the congregation and clergy. Taking the initiative to dialogue with R/S clergy would also benefit genetic counselors by further educating themselves in the traditions of that particular R/S belief system. This would allow genetic counselors an additional opportunity to become more sensitive and empathetic to specific R/S traditions, resulting in an increase in the quality of care provided.

Study Limitations and Research Recommendations

The present study has several limitations. First, the sample is limited, as both female participants and diverse races and ethnicities are vastly underrepresented. Second, using NVIVO 9.0 as a method of data analysis has inherent limitations due to categories and themes being dependent on the observations of the user. While using multiple researchers to categorize data minimizes bias, it is impossible to eliminate all bias when creating themes from qualitative data. Therefore, the potential variability in the data dependent upon the observations of the researcher is a limitation to this study. Third, the sample may have selection bias. While more than 70 Protestant congregations were contacted and invited to participate, only the congregations where clergy spoke with the first author on the phone participated in the study. A larger sample size may have been achieved with a different recruitment method. Another limitation is that qualitative data are not intended to be generalized to the population of interest. Therefore, only tentative conclusions can be drawn from the present findings.

Discussing R/S issues is a complex and delicate task, especially when the discussion encompasses R/S doctrines, such as Creation, the purpose of life and God’s will. While the

authors' of this study admit that the contents herein barely scrape the surface of the many issues involved in the ongoing conversation of religion and genetics, the results help to lay the groundwork for future studies that explore the role R/S clergy play in the field of genetics.

Future research directions should include the purposive interviewing of minority populations, including women clergy and clergy from non-Caucasian racial/ethnic groups. Additionally, it is very important to identify non-Protestant R/S perspectives concerning genetics. It would also be beneficial to quantify the number of genetic counseling patients who identify with a specific religion and what fraction have sought guidance or support from a R/S leader, and to explore the reasons patients have for seeking or not seeking R/S counsel.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1Participant demographics ($N = 8$)

Variable	n
Age	
31–36	1
37–42	0
43–48	0
49–54	2
55–60	4
61–66	1
Ethnicity	
Caucasian	7
Multi-ethnic	1
Gender	
Male	7
Female	1
Protestant Denomination	
Baptist	1
Christian Church	1
Episcopal	1
Lutheran	1
Mennonite	1
Wesleyan	1
United Methodist	2
Highest Level of Education	
Four year undergraduate degree	2
Master of Divinity	5
Ph. D./Doctor of Ministry	1
Years Since Most Recent Degree	
2–5	1
6–10	0
11–15	2
>15	5
Number of Continuing Education Opportunities per Year	
1	3
2–5	4
6–10	1

Table 2

Educational experiences concerning genetics of Protestant clergy participants (*N* = 8)

Responses
<ul style="list-style-type: none">• “Not Applicable” (i.e., no experience) - 2 participants• “Bioethics class in 1978”• “Biology 101 in college and [was a] College Biology Teacher 5–6 times within last 10 years”• “College course called [name of course] touched on genetics, Professor talked about eugenics and dangers of gene selection, mostly negative. Seminary Ethics course included in a study of biotech and genetics. More nuanced-recognizing potential benefits but also abuses. This was just a small segment of the class.”• “Some study as a psychology minor”• “Medical ethics, Christian ethics, biology and anatomy classes at an undergraduate level, on-going interest in science/health issues considering the pastoral care aspects of genetic testing”• “First time I approached genetics was in high school-probably biology class. In my [name of] degree program genetics and reproduction were core classes along with biology and organic chemistry.”

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