The Role of Religion and Spirituality in Genetic Counseling:

A qualitative interview-based study on genetic counselors' recognition and use of the categories of religion and spirituality in their practice.

Emma J. Paddock
MA Religious Studies, Bioethics Option
McGill University
July 2022

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of Master of Arts.

Acknowledgements:

I would like to acknowledge and thank my thesis supervisors Jennifer Fishman and Daniel Cere for supporting me through this process. Dan, thank you for taking me on as a student so I could enter the program and Jennifer thank you for your continuous edits and encouragement. I would also like to acknowledge and thank the School of Religious Studies for awarding me the Graduate Entrance Scholarship, the Birks Award, as well as allowing me the opportunity of a Teaching Assistantship. I also received the I. M. Rabinowitch Fellowship through the Bioethics Unit. Without this financial support I would not have been able to complete this thesis.

I also must extend a huge thank you to all my friends and family who have supported me during this degree. I would like to especially thank my sister Zoë and my friends Raph and Ali who have received numerous phone calls during the past two years and have provided endless support, edits, and comfort. To my roommates, Katey and Kiara, thank you for the numerous hugs and shared meals that have been required to nourish me through this process. And thank you to Kevin, for your encouragement and cuddles. And finally to my parents and grandparents who raised me to understand that I have the capacity and ability to accomplish anything.

Contribution of Authors:

I, Emma Paddock am the sole author of every chapter of this thesis, with the editing input of Dr. Jennifer Fishman.

Table of contents:

Abstract

English:

Religion and spirituality (R/S) has a limited but important role in genetic counseling practice. For those receiving genetic counseling, religion and spirituality can serve as a heuristic and as a shaper of one's worldview in the face of uncertainty and illness. However, there is a lack of consensus regarding the role of R/S in genetic counseling. This thesis explores the role of R/S in genetic counseling practices through both the views of individual genetic counselors and through addressing their views on their practice including R/S within the institutions in which they work.. Through qualitative interviews with 13 genetic counselors about the role of religion and spirituality in their practices, I found that while R/S does not come up consistently, it does arise. As well, training surrounding R/S in genetic counseling is lacking and inconsistent. Overall, religion/spirituality is a blind spot in the practice of genetic counseling operating as a tacit, informal, and varied phenomenon. However, it is one that can shape both practitioners' and clients' decision making and ability to make sense of genetic information in genetic counseling. Therefore R/S in genetic counseling practice deserves more resources, continued education, and research attention in the future to explore its limited role and utility.

French:

La religion et la spiritualité (R/S) occupent un rôle limité mais important dans la pratique de consultation génétique. Pour ceux qui reçoivent des soins en consultation génétique, la religion et la spiritualité peuvent agir comme outil heuristique et servir à guider leur vision du monde face à l'incertitude et à la maladie. Cependant, il n'y a point de consensus lorsque nous examinons le rôle joué par la R/S dans la consultation génétique. Cette thèse explore le rôle de la R/S dans la pratique de consultation génétique aux niveaux institutionnel et personnel. Par le biais de treize entrevues qualitatives conduites auprès de consultants génétiques concernant le rôle de la religion et de la spiritualité dans leur pratique professionnelle, j'en suis arrivée à la conclusion que même si la R/S n'est pas soulevée systématiquement, elle est parfois abordée. Par contre, la formation sur le sujet est manquante et incohérente en consultation génétique. Globalement, la R/S est considérée comme un angle mort dans la pratique de consultation génétique puisqu'elle opère de manière informelle, tacite et qu'elle est un phénomène diversifié pouvant influencer les

décisions des professionnels et des clients. Malgré tout, elle peut avoir un impact sur les décisions et la capacité à accorder un sens à l'information donnée en consultation génétique, tant pour les praticiens que pour les clients. Par conséquent, la R/S dans la pratique de consultation génétique mérite plus de ressources, de formation continue, et d'être l'objet de futurs projets de recherches afin d'explorer son rôle limité et son utilité.

Chapter 1: Introduction

The religious and spiritual beliefs and practices of patients are significant factors in coping with serious illness, making ethical decisions about treatment options, and in decisions about end-of-life care (Puchalski, 2001, Post et al, 2000). While there has been significant research and discussion of the role of spirituality and religion in other medical fields including family medicine (Koenig, 2000), there has only been cursory research on how genetic counselors address the role of religious belief and practice in their counseling practice.

Genetic counseling aims to provide guidance to clients who either need or have received genetic testing to communicate sensitive, uncertain, and technically complex genetic information to the client (Weil, 2003). A limited body of existing literature has surveyed genetic counselors to determine how comfortable they are with addressing religious beliefs and practices in their work and whether they actually do raise these concerns (Reis et. Al 2007). However, there is very little in-depth research on how religion and spirituality is enacted in genetic counselling. While there are guidelines for general clinical practice, such as the HOPE spiritual assessment (H: Sources of hope, meaning, comfort, strength, peace, love, and connection; O: Organized religion; P: Personal spirituality and practices; E: Effects on medical care and end-of-life issues) (Anandarajah and Hight 2001; Reis et. Al 2007), the specifics of addressing spirituality in genetic counseling are not elaborated on. Additionally, the graduate training provided for genetic counseling concerning how to address R/S is not regulated and varies considerably by institution (Murray et al. 2020). This thesis contextualizes genetic counseling as a field which stands out in medicine due to its key elements of uncertainty, acute medical crises, and relational as well as psychosocial practices. Furthermore, considering the importance of genetic information and its impact on many facets of people's lives, including reproduction, aging, and end-of life, R/S matters may be particularly pertinent to understanding how clients reconcile new genetic medical information with their worldview.

Through an interview-based study of 13 genetic counselors from four Canadian provinces, I asked questions regarding respondents' genetic counseling practices with reference to addressing R/S with clients as well as the genetic counselor's own R/S affiliations. The themes that emerged from my interviews and which also form the results chapters are:

1. Goals of genetic counseling: What do the participants mention as the goals of their profession both generally and personally and how does religion and spirituality play a role in these goals?
2. Genetic counselors' personal beliefs and how they relate to their practice, and
3. Resource Availability/Management with regard to religion and spirituality in genetic counseling.

Preceding the results chapters, is a comprehensive literature review as well as a chapter on the methods of the study. The results and discussion chapters are then followed by the concluding chapter.

1.2 Summary of Findings

The results of this study supported existing literature, finding that there is limited consensus on how to address R/S in genetic counseling practice. Respondents seemed particularly interested in participating in the study due to the novel nature of directly addressing the inclusion of R/S within genetic counseling practice. However, respondents did state that they had encountered R/S in their practice with patients, particularly in the prenatal context regarding termination of pregnancy but also as something that came up when clients were trying to incorporate genetic illness into their worldview. Therefore, addressing R/S in genetic counseling practice is a way for the genetic counselor to acknowledge the clients' worldview to help them adapt to new genetic information. Respondents also reported inconsistent education on R/S in their graduate training with some reporting specific lessons on the topic and others seeing it lumped in with training on cultural sensitivity. While respondents did not overwhelmingly communicate that they were interested in consistently addressing R/S with clients, especially given their time constraints in a session, many reported that they wished for more continuing R/S education as well as more knowledge of institutional resources geared toward addressing R/S with clients. Given the absence of consensus on the recognition of the frequency and importance of R/S for clients, as well as previous literature showing both the theoretical and practical use of R/S in medicine and genetic medicine specifically, more tools and education should be available for incorporating R/S into genetic counselling practice.

Chapter 2: Literature Review

A limited body of existing literature has surveyed genetic counselors to determine how comfortable they are with addressing religious beliefs and practices in their work and whether they actually do raise these concerns (Reis et al. 2007; Fanning, 2016; Sagaser et al. 2016). However, there is little in-depth research on how a counseling approach to religion and spirituality is enacted in genetic counseling. While there are guidelines for general clinical practice, such as the HOPE spiritual assessment (Anandarajah and Hight 2001; Reis et al. 2007), the specifics of addressing spirituality or religion in the field of genetic counseling have not yet been a focus of research.

I will begin with a discussion of the history of genetic counseling, outlining the evolution of genetic counseling practice paradigms. This will be followed by a discussion of the modern ethical and psychosocial debates in genetic counseling that frame the goals of genetic counseling and the perception of religion and spirituality in genetic counseling and general medicine. Finally, I will provide definitions of religion and spirituality for the purposes of medical research.

2.1 History of Genetic Counseling: From Non-Directiveness Forward

While my research involves questions about current genetic counseling practices, I believe it is important to acknowledge the complicated history of genetic counseling and to situate my research within that historical context. Alexandra Minna Stern's book, titled *Telling Genes* (2012)*,* as well as the article *"*What have we been trying to do and have we been any good at it? A history of measuring the success of genetic counseling" by Robert G. Resta (2019) provide some valuable historical background to the field. Particularly relevant in the context of this thesis, is the evolution of the prevailing paradigms of genetic counseling practice as it pertains to addressing religion and spirituality.

Genetic counseling came about in the 1940s with the coining of the term *genetic counseling* by Sheldon Reed in 1947 at the University of Minnesota (Stern, 2012). At the time, it was only performed by medical geneticists and doctors (and was therefore very male-centered given the era) and had yet to become the distinctive professional field we know today. Furthermore, prior to the genetic counseling practice, genetic medicine was almost entirely defined by the eugenics turn in the early 20th century wherein genetic medicine (especially in the prenatal context) was practiced to produce genes perceived as good and reduce occurrences of genes in the population seen as undesirable. Then, in the 1960s and 70s the field developed into what we know now: an independent and autonomous master's level profession (Stern, 2012).

A group of women played a pivotal role in reinventing the entire profession (Stern, 2012). The world's first genetic counseling master's program was developed in 1969 by Melissa Richter at Sarah Lawrence College in New York State, in part so that women could take part in an ever-growing field and pursue "an advanced degree with practical applications" (Stern, 2012, p.102). This is not surprising given that modern genetic counseling arose at a time when there was growing political and societal attention regarding women's issues especially with "second-wave feminism, the de-criminalization of abortion, discoveries in medical genetics, the growth of prenatal services and genetic testing, and changing attitudes toward the physician-patient relationship" (Stern, 2012, p.103). Thus, most of the key players in the genetic counseling at that time were white middle to upper class women, a trend which still largely characterizes the demographics of the profession to this day.

Many students who graduated during this time stated that they were taught to think outside the frame of the traditional medical hierarchy and treat physicians as their equals (Stern, 2012). They also emphasized the view that genetic counseling should be viewed as a "calling" as it allowed "them to combine their various interests and talents—in genetics, health care, human psychology, and reproductive issues—into a multidimensional whole" (Stern, 2012, p.120). To the new graduates, the emotional care of other humans was just as important as the science. Regarding this, Stern makes the point that genetic counselors in both their professional capacities and as primarily women, fall under the category of emotional laborers which helps to elucidate the gender and psychological profile of genetic counselors of the time as well as today (Abacans et. Al, 2019; Stern, 2012; Reis et. Al., 2007):

> [g]enetic counselors are a unique variant of emotional laborers, carrying out a kind of work that does not involve hands-on clinical care or medical treatment… they provide information and a platform for discussion about health conditions for which there frequently is no cure or treatment. Genetic counselors want to do emotional labor, but on

> a level where they experience more autonomy than workers in other kinds of service positions (Stern, 2012, p.122).

The emphasis on autonomy is important as it underscores the view that genetic counselors hold a distinctive and often independent place within the medical system which contributes to considerations of resources regarding religion and spirituality.

The aforementioned emotional component also connects to the current genetic counseling practice paradigm; the psychosocial paradigm. The psychosocial paradigm addresses the historical and current conversations surrounding ethics in genetic counseling revolving around the question of non-directiveness and patient autonomy. Non-directiveness is the practice of not influencing the decision of the client in any way, but rather allowing the client to make their decision free of any argument or coercion on the part of the counselor (Stern, 2012). Jon Weil, author of *Psychosocial Genetic Counseling*, one of the most well-known genetic counseling textbooks, did not embrace non-directiveness in an unqualified way, but recognized that it was an important way to underscore that genetic counseling should be noncoercive, nonprescriptive, and avoid giving eugenic advice (Stern, 2012). In the contemporary context, "many genetic counselors have come to the conclusion that non-directiveness can easily constrain them by emphasizing what they should *not* do, thus limiting "the role of the genetic counselor to that of information provider" and inhibiting "the use of the full range of relevant counseling techniques"(Stern, 2012, p.142, emphasis in original). There is now a growing body of research by genetic counselors that argues against the use of non-directiveness and for the use of the word client rather than patient emphasizing "a less clinical and more psychological approach to the person being counseled" (Stern, 2012, p.144). Qualifying or altogether abandoning the non-directive counseling paradigm and recognizing the patient as client enables enables genetic counseling to move beyond a strictly medical paradigm. Moving beyond the medical paradigm then allows the counselor to address more psychosocial aspects of the whole person (of which religion and spirituality can play a part) with the acknowledgement of beneficence, consent, and client autonomy (Stern, 2012).

Robert G. Resta divides the history of genetic counseling into three time periods:

> "1) 1947–1980, when the focus was primarily on prevention of disability, 2) 1981–1995, when the rationales for counseling began to shift and the first studies on the psychosocial effects of genetic counseling started to appear, albeit still largely focused on

> reproduction, and 3) 1996 - Present, when genetic counselors increased their presence in oncology, cardiology, and other non-reproductive areas of genetic counseling" (Resta, 2019, p. 300).

Resta explores the prevailing genetic counseling attitudes of the time but also places them in the larger "genetic counseling sub-specialty being assessed; the sociocultural and economic milieu; and the prevailing ethical paradigms" (Resta, 2019, p. 300). While the overall history of genetic counseling is important to this study, Resta's discussion of the third time period, the present, is most pertinent to this study as it provides us with a greater understanding of where genetic counseling currently sits within broader health care structures.

By late 1992 and early 1993, the certification of genetic counselors was formally separated from that of medical geneticists. The American Board of Genetic Counseling (ABGC) was created to certify genetic counselors rather than the American Board of Medical Genetics (ABMG). Another important step in the making of genetic counseling as an independent and self-referential field was the introduction of the Journal of Genetic Counseling in 1992 under the National Society of Genetic Counselors (NSGC) where genetic counselors could publish their own research specifically on their practice, as well as create a forum to define genetic counseling by genetic counselors themselves. As such, "it is only over the last 20 years or so that well-designed, rigorous outcome studies have been undertaken on a regular and frequent basis," on the topic of the effectiveness of genetic counseling (Resta, 2019, p. 305).

2.2 Ethics and the Psychosocial Aspect: General Goals of Genetic Counseling

What is genetic counseling? And what is its place within the medical system? The answers to these questions will vary depending on whom you ask. However, there are some sources that provide particular definitions and guidelines which shape the North American conception of genetic counseling and its goals. For one, there is the Accreditation Council for Genetic Counseling (ACGC) that recently updated the genetic counseling Practice-Based Competencies (PBCs). Because of the limited scope of this study, I will only be referencing the PBCs which relate to religion and spirituality. There is also the National Society of Genetic Counselors in the United States (NSGC), the American Board of Genetic Counseling (ABGC) and the Canadian Association of Genetic Counselors (CAGC) with each group having specific membership requirements and different definitions of genetic counseling.

Religion and spirituality (R/S) often enter into the discussion of genetic counseling practice in the psychosocial realm. Weil argues that the psychosocial framework is what should be used rather than non-directiveness (Weil, 2003). Accordingly, what are the current goals of genetic counseling as a profession, specifically with regard to psychosocial genetic counseling? In the Canadian context there is very little literature on genetic counseling. However, on the Canadian government's public health website, they state that genetic counseling is available to "help you to manage stress linked to genetic testing" (Government of Canada, 2013) .They offer a safe, supportive, confidential environment where you can share your personal and family medical history and explore the emotional aspects of both genetic testing and the results of tests (Government of Canada, 2013). Also within the Canadian context, the Canadian Association of Genetic Counselors (CAGC) was formed in 1987 and is overseen by the Canadian Board of Genetic Counselors (CBGC). Currently to practice as a genetic counselor in Canada one must be accredited through the CBGC. However,

> [t]he genetic counselling profession is currently unregulated in Canada and, as such, practitioners are not governed by provincial and territorial legislation, which ensure safe, competent, and ethical practice in the interest of public protection. The national certification credential is an important basis for the evolution of professional legislation and regulation in Canada (Canadian Board of Genetic Counselors, 2022).

The current state of regulation may contribute to the relative dearth of context specific guidelines in genetic counseling. Currently in Canada, genetic counseling services are accessed on a referral only basis, as are most specialties in the Canadian system. It is also important to note that there is a shortage of genetic counselors in Canada with only about 270 positions currently existing nationwide (Abacans, 2019). This lack of research on the goals and effectiveness of genetic counseling in any context (Resta, 2019), not to mention the Canadian context, also effects the lack of standardized tools or education regarding R/S in genetic counseling.

2.2a R/S in Psychosocial Practice

To date, there is no research or information specifically on ways of engaging religion or spirituality to make genetic counseling more encompassing of the person as a whole. It is most often seen as a small part of the larger whole of psychosocial genetic counseling practice. However, much of the literature on religion and spirituality, in general medicine as well as in genetic counseling, cites religion and spirituality as a coping mechanism that helps to reduce suffering (White, 2009; Reis et. Al. 2007, Koenig, 2009; Puchalski et. Al. 2014). In connection to the use of R/S to reduce suffering in general medicine, citing Nathaniel Comfort (2012), Resta points out that "reducing suffering" has always been a justification and ethos in genetic counseling; "genetic counseling was the most effective available means" of reducing suffering even if in deference to the principle of non-directiveness many genetic counselors would not explicitly state this as their goal (Resta, 2019, p. 305). Can genetic counseling develop approaches to effectively engage the domains of religion and spirituality in pursuing the goal of reducing human suffering in this complex area of human vulnerability?

In the article "2013 Review and Update of the Genetic Counseling Practice Based Competencies by a Task Force of the Accreditation Council for Genetic Counseling", Doyle et al. (2016) compare the new PBCs to those released in 1996. In these new PBCs are four domains: "(I) Genetics Expertise and Analysis; (II) Interpersonal, Psychosocial and Counseling Skills; (III) Education; and (IV) Professional Development & Practice." Within these are a total of 22 competencies (Doyle et. Al 2016, p. 873). Within the second domain, there are two PBCs that could be seen to relate to R/S, however there are none that make direct reference to it:

> 11. Promote client-centered, informed, noncoercive and value-based decision-making.
>
> 13. Apply genetic counseling skills in a culturally responsive and respectful manner to all clients (Doyle et. Al, 2016, p. 875).

Recognizing clients' values and their cultural backgrounds includes ascertaining whether R/S is important in their life. Similarly, within the fourth domain there are two competencies that could be connected to addressing R/S in genetic counseling:

> 20. Demonstrate a self-reflective, evidenced based and current approach to genetic counseling practice.

22. Establish and maintain professional interdisciplinary relationships in both team and one-on-one settings, and recognize one's role in the larger healthcare system (Doyle et. Al, 2016, p. 875).

Twenty and twenty-two are differently connected to R/S than 11 and 13, in that they relate to the professional more than the client. Regarding self-reflexivity, many genetic counselors need to reflect on their own religious and spiritual leanings as it relates to their practice. As well, maintaining professional relationships requires knowledge and respect of coworkers' values, and may also include working with a spiritual care professional in team settings (Geller et. al, 2009).

In their article, "A New Definition of Genetic Counseling: National Society of Genetic Counselors' Task Force Report" Resta et al. (2006) make the point that all of these practice definitions "are not created in a social vacuum but rather reflect larger social trends, the socioeconomic background of genetic counselors, advances in medical technology and scientific knowledge, changing ethical values, and the motivation behind formulating a given practice definition" (Resta, 2006, p. 80). Genetics as an area of medicine is rapidly evolving and so too must be the way it is defined and regulated. The NSGC therefore aims to define genetic counseling in a manner that asserts its relevance, utility, and value to society (Doyle et. al 2016). The definition the NSGC settles on is quite short and generally reflects the psychosocial or counseling aspects of the profession: "The NSGC definition of genetic counseling states that genetic counseling is the process of helping people understand and adapt to the medical, psychological, and familial implications of the genetic contributions to disease." (Doyle et. al, 2016, p.79) 'Adapt' is the key word here, as it shows that genetic counselors must understand many aspects of their clients' lives in order to help them create meaning out of, cope with, and adapt to difficult information. A similar definition and goal are echoed in B.B. Biesecker's piece, "Goals of genetic counseling" (2001) which emphasizes "a psychoeducational paradigm for genetic counseling," in which understanding is promoted, informed consent is achieved, and decision making is facilitated with the least amount of psychological distress, the greatest amount of personal control for the client and the best adaption to stress-inducing events (p.327).

The current ethical concerns of practice are particularly rooted in an effort to turn away from the eugenic past of genetic medicine. Clarke and Wallgren-Pettersen (2019) address this in "Ethics in genetic counselling." Large questions surround predictive genetic testing, which is available, but is often testing for conditions for which there are not yet any available treatments, or prenatal testing where the only available prenatal intervention would be the termination of the pregnancy. The authors posit that the genetic counselor wants to be sure not to coerce or manipulate the client, leaving room for their autonomy to be respected. In this case, rather than non-directiveness, as has been previously referenced, “a practitioner has to provide the relevant information in an accessible way and raise factors for consideration that the patient may have not yet considered” (Clarke and Wallgren-Pettersen, 2019, p. 12). Specifically with regard to R/S, there are ethical concerns in making sure that clients feel safe and respected when voicing their R/S concerns or views. Clarke and Wallgren-Pettersen place R/S concerns in their section on multiculturalism. For example, they reference consanguineous families (for cultural and R/S reasons) in the UK South Asian population that need understanding to achieve better health outcomes rather than judgement (2019). The article also reminds practitioners to recognize that ‘religion’ of any sort is not monolithic or homogeneous and no one is helped by assumptions or generalities in genetic counseling (Clarke and Wallgren-Pettersen, 2019).

Discussing ethical goals for genetic counseling, Baty states that one should also “[a]ccept and validate clients’ experiences (embodied knowledge) to help increase their self-knowledge, autonomy, and decision-making capacity” (Baty, 2009, p. 213). Genetic counseling should “[d]ecrease time pressure… Explore personal relevance and implications of information before making a decision [and] use self-affirmation techniques (e.g., reflecting on important values) to reduce defensive processing of health risk information” (Baty, 2009, p. 213). Essentially, the genetic counselor should be practicing in a way which empowers the client to make decisions that are best for them and to give them the best tools for coping, tools which can come from both internal and external reference points in the client’s context. Accomplishing these goals is challenged by lack of organization and preparation on the part of the genetic counselor, lack of time with patients, lack of attention to cultural factors, and inability on the part of the genetic counselor to admit to a lack of knowledge (Veach et al, 2003; Baty, 2009). In addressing spirituality with patients in palliative care, Puchalski (2014) list similar barriers, such as lack of time, lack of training in spiritual care, as well as fear of not having enough knowledge to address spiritual concerns with a patient.

2.3 Whole Person or Patient Care

Another ethical imperative sometimes related to R/S and genetic counseling is the idea of whole person or patient care. In genetic counseling and genetics in general it is easy to reduce the client to their genetics or their illness, especially given the short period of time a genetic counselor has with the client (Jackson, 2009). For the purpose of this research, I provide a short discussion below of some of the definitions and ideas surrounding whole person care.

In "A New Vision for Healthcare," the first chapter of *Whole Person Care,* (2017) Dr. Tom A. Hutchinson argues for the recognition of the person beyond the context of 'patient' within the medical care system, especially in how they respond to illness and health practices;

> The larger question is whether there is room in medicine for the underlying drive that led to the behaviors I describe, to respect (and even love?) people for their unique characteristics, wishes, and longings that they bring with them into medical care and to see this uniqueness as a source of strength and energy that needs to be tapped in maximizing quality of life (Hutchinson, 2017, p.4).

He uses the work of Virginia Satir, who ran workshops on family therapy that revolutionized the way he thought about approaches to helping and healing others. The ideal is to create a space where nothing is pathologized, and everything is considered valuable and useful (Hutchinson, 2017). Hutchison argues that "separating the person from the diagnosis has therapeutic value that is unrelated to whether we can cure the disease" (Hutchinson, 2017, p.6). This point is particularly helpful in thinking about genetic counseling as it is often the duty of a genetic counselor to communicate a diagnosis that has no cure. Thus, the client can only be helped through gaining understanding of who they are outside their diagnosis in order to help them cope and adapt. The separation, yet recognition of both the person and the disease, "opens the way for growth and development of the healthy person with a disease, as opposed to a diseased person" (Hutchinson, 2017, p.6). Acknowledging and addressing the separation does however complicate the job of the medical professional, making them both responsible for curing disease, if possible, and "fixing what can be fixed" for the facilitation of healing (Hutchinson, 2017, p.7). In this way, the patient or client can be supported in maintaining their identity as a person rather than a disease, throughout treatment.

So how does this concept of whole person care relate to R/S specifically? In "Why Spirituality in Palliative Care", Christina Puchalski and colleagues (2014) specifically discuss the utility of spirituality in palliative care. They argue that "[i]llness and dying are essentially spiritual processes in that they often provoke deep questions of meaning, purpose, and hope" (Puchalski et al, 2014, p.3). Their definition is similar to above definitions that operationalize the category of spirituality for use in medical contexts. In another article with different colleagues, Pulchaski argues that because suffering is increased if it is not understood as "suffering with meaning," it is just as important for clinicians to talk with patients about spirituality as it is to address the physical aspects of care (Puchalski et al., 2017, p.5). For them, addressing spirituality is a step in clinicians being attentive to all the dimensions of suffering. The recognition of spiritual or existential distress is just as important to healing as the physical aspects. In recognizing the spiritual concerns of patients, Puchalski et al. (2017) also argue that the clinician helps the patient to find meaning in their illness as well as a sense of dignity and purpose. In recognizing more than just the illness of the person, by recognizing the whole person, the clinician contributes to healing in other senses than the physical, thus contributing to the overall well-being of the patient (Puchalski et al., 2014; Koenig, 2001; Hutchinson, 2017; White, 2009). Similarly Doehring, argues that "[g]iven the prevalence and negative health outcomes of religious, spiritual, and moral struggles, health care teams risk neglect by not finding ways to holistically help such patients" (2019, p. 73).

Puchalski et al. (2014) then explore the palliative care guidelines established by the National Consensus Project and the National Quality Program. In both sets of guidelines, they are split into domains, five of which focus on the spiritual and religious dimensions of care. These guidelines recommend using a standardized instrument to identify a spiritual background, the knowledge and use of pastoral care contacts in religious or spiritual communities, and referrals to professionals with specialized knowledge in spiritual or existential issues such as pastoral or spiritual care providers (Puchalski et al., 2014). These recommendations could be generalized to genetic counseling which often confronts similar concerns in dealing with serious illness and the existential uncertainties surrounding suffering.

2.4 Religion and Spirituality in Medicine and Genetic Counseling

More broadly, I surveyed literature on perceptions and arguments for the utility of addressing spirituality in general clinical practice. The debate on the utility of spiritual assessment in medical care has been prevalent in medical literature particularly since the 1990s (Larson and Larson 2003; Murray et al., 2020). There are two aspects of this debate; the perspective of the health-care provider and the perspective of the patient.

Harold Koenig, a psychiatrist and director of the Center for Spirituality, Theology and Health at Duke University Medical Center, is a strong proponent of the acknowledgement and engagement of religion in patient care. In “Religion, Spirituality, and Medicine: Application to Clinical Practice” he argues that if physicians do not acknowledge this part of the patient, they are not practicing whole person care (Koenig, 2000). For Koenig (2000) it is a mistake to not acknowledge the spiritual aspect of the human in clinical care.

In philosophical terms, Puchalski (2010) in “Religion, Medicine and Spirituality: What We Know, What We Don’t Know and What We Do” argues that “[b]ecause illness and injury disrupt a patient’s life in ways that extend beyond the body, encompassing families, communities, and a patient’s religious commitments, a commitment to caring for whole persons must entail going beyond the care of the body” (Puchalski 2010, 48). She goes beyond Koenig and argues that health care professionals take an oath to provide “compassionate holistic care” and so are obligated to address spiritual matters at least when they arise. However, Puchalski’s argument is not grounded in evidence-based study, but rather in ethical precepts (Puchalski, 2010; Puchalski et al., 2014). Further, Puchalski et al. (2014) see compassion as an aspect of spirituality. In this way, physicians providing compassionate care are engaging in a spiritual act.

I found a limited amount of research regarding genetic counselors’ perspectives on religion and spirituality in their practice. Reis et al. (2007) surveyed genetic counselors on their spiritual assessment practice in “Spiritual Assessment in Genetic Counseling”. Reis et al. was also referenced in almost all the other studies I found, cited about the significance of spirituality in genetic counselling practice. This is likely because of its concrete set of data and description of clear tools rather than a more philosophical discussion of the utility of religion and spirituality in healthcare settings. The study used a self-administered questionnaire distributed via email with both Likert scale questions and some open-ended questions (Reis et al. 2007). It also inquired about the counselors' personal spirituality and focused specifically on their use of the HOPE assessment tool.

The Reis et al. (2007) study addresses the tools that are available to genetic counselors and whether they in fact feel comfortable addressing spirituality, rather than what their actual practice regarding recognition of spirituality involves. It also discusses the utility of addressing spirituality in genetic counseling, citing three studies that indicate patient interest in the recognition of spiritual concerns in genetic counseling. The first study found that 77 % of seriously ill patients think physicians should consider their spiritual concerns; the second found that 53 % of seriously ill patients think physicians should *discuss* spiritual needs; and the third study of adult out-patients found that 66 % of respondents thought that inquiries by physicians into their spiritual lives would increase trust within the relationship (Ehman et al., 1999; Kaldjian et al.,1998; King and Bushwick, 1994; Reis et al., 2007).

The use of these studies shows that Reis et al. think that spiritual assessment may be of use in genetic counseling. Reis et al. then outline that their results indicate that the most common reason that genetic counselors engage in spiritual assessment (76.4%) is that the patient has brought up a spiritual or religious concern themselves (2014, p. 45). The second most commonly-cited reason for discussion of spiritual or religious topics are counseling sessions "that involve termination" of a pregnancy (41.7%) (Reis et al.2014, p.45). The third most commonly-cited reason is sessions where end of life concerns arose (29.9%) (Reis et al.2014). The study also asked the participants about their own religious or spiritual affiliation, with the majority citing some sort of Christian affiliation or moderate to strong "self-perceived spirituality" (Reis et al.2014, p.44). Finally, the study found that 20.2% of respondents saw a "low perceived relevance" of spiritual assessment in their practice while 37.3% cited they had low comfort with spiritual assessment. Furthermore, the main reason counselors selected for not assessing spirituality was lack of time in a genetic counseling session (45.7%). Respondents also cited perceived client discomfort as a barrier (27.6%) (Reis et al., 2014, p. 45).

The HOPE spiritual assessment tool cited in the Reis et al. article is a set of questions related to the mnemonic HOPE standing for "H—sources of hope, strength, comfort, meaning, peace, love and connection; O— the role of organized religion for the patient; P—personal spirituality and practices; E—effects on medical care and end-of-life decisions" as mentioned above (Anandarajah and Hight, 2001). The assessment was developed by Anandarajah and Hight for physicians and is regularly cited in literature dealing with medical care and spirituality. The authors point out that their survey works better if the practitioner first understands their own spiritual beliefs or leanings. However, the aspect of the assessment that Reis et al. does not include in their study is that the HOPE system also advocates for informal assessment wherein practitioners are encouraged to interpret patients' use of symbolic or metaphoric language as it pertains to spirituality. This is intended to circumnavigate barriers due to use of overly specific vocabulary. It is worth noting though, that this assessment is meant for physicians in a routine medical encounter, and therefore may not be the best suited to genetic counseling practice despite often being referenced as an option. Reis et al. also surveyed their respondents on their perceived comfort and utility in response to all four of the HOPE survey categories. Overall, "counselors indicated highest perceived relevance and comfort with questions relating to sources of hope, meaning, and connection" (Reis et al.2014, p. 48).

From the perspective of the patient, studies show that the majority of patients are in favor of their spiritual concerns being addressed in some way during their medical care (Ehman et al. 1999) and specifically when receiving genetic counseling (Bartenbaker Thompson et al. 2016, Murrey et al. 2020). Given the undetermined nature of spiritual assessment in genetic counseling, I also searched for literature assessing how patients react to spiritual discussion in the context of genetic counseling. Ultimately the relative consensus of the interview-based study in "Be Prepared if I Bring It Up": Patients' Perceptions of the Utility of Religious and Spiritual Discussion During Genetic Counseling" was that many patients supported it but that it requires a personal and tailored approach rather than general approach (Thompson et al. 2016).

The Reis study and the use of the HOPE survey in genetic counseling are discussed and problematized in "Genetic Counseling and Spiritual Assessment" a chapter by Joseph B. Fanning in *Normative and Pragmatic Dimensions of Genetic Counseling* (2016). Fanning cites Richard Sloan's *Blind Faith: The Unholy Alliance of Religion and Medicine* (2006) which argues that studies like Reis et al., and those the Reis et al. study cites, are not methodologically rigorous and therefore questionable. Accordingly, using their conclusions for any decision-making about practice is not recommended (Fanning, 2016). However, Sloan's discussion references medicine more generally and does not mention genetic counseling directly (Fanning, 2016). Fanning, building on Sloan's claims that data showing that patients would like religion and spirituality addressed in medicine and genetic counseling is unsound, concludes that there are potential harms of spiritual assessment in genetic counseling and that these may be severe enough to preclude potential benefits (Fanning, 2016). It is important to note that only *structured* spiritual assessment is being discussed here, not informal. The potential risks listed are: "(1) lack of relevance, (2) patient privacy, and (3) misunderstanding and manipulation of patients" (Fanning 2106, p.120). Given these concerns, Sloan and Fanning feel that spiritual assessment need not be a separate aspect of psychosocial care, but rather one of the many things that may come up with a good cultural competency. In this way a health care provider (HCP) may not overstep bounds of patient privacy or waste already limited time on something that may not be relevant.

There are power structures inherent in HCP and patient relationships, and the use of a structured and routine spiritual assessment may manipulate the patient into bringing spirituality into something they may not have previously considered it relevant to. As well, it may make the discussion more in terms of what the HCP deems relevant rather than what the patient prioritizes (Fanning, 2016). Conversely, bringing up R/S can confer respect for what is important to the patient and can be helpful in patient decision-making as cited in two studies by Reis et al. (2007) and Fanning (2016). However, Fanning concludes that "genetic counselors already have a large influence on the shape of the conversation[,]" therefore, "to add a spiritual assessment to the pedigree and other intake procedures gives the genetic counselor control over one more vocabulary" (Fanning, 2016, p. 124). Fanning decides that the potential harms of structured spiritual assessments in genetic counseling are large enough to outweigh any benefits (2016).

As mentioned previously, genetics is a specific branch of medicine that may raise an array of existential questions due to uncertainty, making addressing patients' spirituality particularly pertinent. In "Making Sense of Genetic Uncertainty: The Role of Religion and Spirituality," M.T. White (2009) argues that it is the uncertain nature of genetic testing, diagnosis, and thus communication that makes ethical deliberation and decision-making in genetics particularly fraught. Genetic testing brings up questions about health, identity, and reproduction and it is often a new decision-making experience for patients, because the decisions are based on probabilistic "prophetic" information and not definitive information (White, 2009, p. 69). Therefore, genetic counselors are tasked with managing the communication of this uncertainty and the perception of risk "as the possibility of a loss" (White, 2009, p. 70). White makes the point that addressing the spirituality of patients can help navigate genetic risk perception and uncertainty as a heuristic strategy to bring meaning to uncertainty. However, given the context of genetic counselling in medicine and its emphasis on patient autonomy, there is of course the danger that addressing spirituality may be seen as infringing on patients' autonomy (White, 2009).

Similar to White (2009), in *A Guide to Genetic Counseling* Baty (2009) briefly discusses the utility of religious and spiritual concerns in the risk communication and decision-making aspects of genetic counseling. The communication of risk almost always leads to some need for decision making. Discussion surrounding decision making is aided by the psychosocial perspective here defined by Baty as:

> establishing rapport and trust, unconditional positive regard, attention to emotional components, congruence of verbal and nonverbal components, counselor genuineness, shared control of the session between counselor and counselee), and the environment (e.g., privacy, comfortable seating, orientation of counselor to counselee(s), [and] adequate time" (Baty, 2009, p. 208).

Therefore, an interactive process that allows the practitioner to assess the patient's needs, understanding, and ability to integrate the information communicated is paramount (Baty, 2009).

According to Baty, risk perceptions are influenced by many things, among them, beliefs about etiology and prognosis which can include R/S (Baty, 2009). Overall, Baty sees the utility of addressing R/S with patients because "It is important for genetic counselors to recognize the diversity of spiritual and religious beliefs…Patients may find that their religious beliefs offer hope and strength, or compound their suffering" (Baty, 2009, p. 218). As well, questions of "playing God" often come up when discussing genetics, life, death, and suffering. However, given White's 2009 study shows that genetic counselors do not often address R/S with patients or refer to pastoral care, Baty recommends referral to pastoral care in the future as pastoral caregivers are already trained to provide spiritual counseling, do spiritual assessment and "help people draw on their religious beliefs to make sense of their circumstances, interpret and affirm patients decisions in view of their religious background, and help cope with tragedy and loss“ (Baty, 2009, p. 219).

2.5 Personal R/S Affiliations of Genetic Counselors

Another aspect of the relationship between medicine/genetics and R/S is that of the religious or spiritual affiliations of the HCP's themselves. In "The Role and Impact of Personal Faith and Religion among Genetic Service Providers" by Geller et al. (2009) this is discussed specifically in reference to the field of genetics. The authors argue that multiple and seemingly contradictory worldviews such as the "scientific" and the "spiritual" can coexist in one individual (Farese, 2005; Tilburt and Geller, 2007), both the patient and the HCP (Geller et al., 2009, p.32). The study measured degrees of religiosity among genetic care providers based off of categories such as the importance of attending religious services and finding comfort in religion or spiritual beliefs. This is a rather simplistic definition of R/S, but as it was a self-reported survey, it makes sense to use an easily communicated measure. The study then questioned whether the HCPs felt comfort or discomfort with their beliefs in the professional setting, both with patients and with colleagues. Overall, most genetics professionals are not religious according to this study's results, whereas about half of US physicians report being religious and spiritual (Geller et al., 2009).

However, a significant minority of genetic service providers are religious and more importantly, rely on religious values to cope with stress. In this minority, Geller et al. found that there was some difficulty in reconciling their beliefs with their practice, as well as feeling they are being ostracized in their professional community as a result of their R/S affiliation. However, it also found that they were able to override their personal faith for "the sake of scientific progress and their professional obligations" (Geller et al., 2009, p. 37). They also felt that their personal faith helps to enhance their practice and ability to aid clients. On the other side of this are those who did not identify as religious and expressed some internal conflict, feeling judgment towards patients who express strong religious belief, or concern that patients will not be comfortable sharing their religious values because of the medical context of the discussion or become defensive of their belief's possible impact on their decision-making process, especially regarding prenatal counseling and termination of pregnancy (Geller et al., 2009). Finally, the study makes recommendations including more education on HCP self-awareness (as seen in the PBCs) and more openness and tolerance between colleagues to improve professional relationships and help to improve culturally competent care. Just as in White (2009), Geller et al. (2009) make the point that genetics, perhaps more than other areas of medicine, forces people, both patients and HCPs to confront fundamental questions about what it means to be human, a topic which is likely to also bring up faith and spiritual beliefs (2009).

2.6 R/S in Genetic Counseling Education

The utility and relationship between R/S and genetic counseling has also been studied in terms of the curricula in graduate training programs in North America in "Genetic counseling graduate training to address religion and spirituality in clinical practice: A qualitative exploration of programs in North America" by Murray et al. (2020). Unlike many sources I found, it includes the Canadian context which makes it more directly applicable to my own research. After asserting the utility of R/S in genetic counseling practice via already mentioned sources such as Bartenbaker Thompson et al. (2016) and Reis et al. (2007), the authors also reference the Accreditation Council for genetic counseling's PBCs which state "An entry-level genetic counselor is expected to be able to 'Identify factors that affect the learning process such as...religious and cultural beliefs"' (Doyle et al. 2016, 877; Murray et al., 2020, p.1246).

Given these arguments, graduate training in genetic counseling in North America should include some mention of R/S in the curriculum. Specifically, the study asked "[h]ow are genetic counseling programs in North America preparing their students to discuss religious and spiritual matters with their patients?" (Murray et. al, 2020, p.1246). They found that almost all programs integrated R/S concerns when discussing patient decision making and then more than half addressed it in regard to patient support (Murray et. al, 2020). As well, concerning learning about pastoral care, students in 92% of participating programs are introduced to pastoral care resources: 33% discuss the pastoral care profession in the didactic portion of the curriculum, and only 58% of the programs "include a lecture from a chaplain regarding spirituality in the medical setting, the role of a hospital chaplain, how chaplains contribute to palliative care, and when/how to refer patients to pastoral care." 33% of the programs facilitate observation of "chaplains and other members of the palliative care team in the hospital setting" (Murray et. al, 2020, p.1248). In this study the sample size was of 12, out of the 33 accredited programs in North America. As well, they interviewed program leadership rather than students which may result in some bias and/or discrepancy in the data in terms of the lived reality of these curriculums.

The study also asked whether structured surveys such as the HOPE survey were included in the curriculum. 41.7% said they taught a specific survey in order to provide tools to their students to address, whereas others taught more general questions. Otherwise, 25% stated they were not aware of spiritual assessments or used intake questionnaires or forms to identify R/S background. Many programs did not address specific R/S beliefs in their curriculum. All surveyed programs however, did teach students to address personal bias in clinical work and more than half relied heavily on clinical rotations to address spiritual concerns (Murray et al, 2020).

So, what do all these statistics mean? Essentially that there is great variation among genetic counseling graduate programs as to how they address R/S in their curriculum and the importance they place on learning specifics surrounding R/S issues in genetic counseling. All stated that genetic counselors should be able to respond if a patient brought up R/S, but only 75% said this was of high importance, and of course, many decided to not participate. As well, many did not evaluate the R/S curriculum after it was taught (Murray et al, 2020).

2.7 Defining Religion and Spirituality

In "Genetic Counseling and Spiritual Assessment" Fanning (2016) also includes a good discussion of the importance of a comprehensive definition of what constitutes religion and spirituality. One of the definitions discussed, and that which is espoused by Anandarajah and Hight, the authors of the HOPE survey, is spirituality as "a complex and multi-dimensional part of human experience. It has cognitive, experiential, and behavioral aspects" (Fanning, 2016, p.105). Fanning examines this definition in his discussion the utility of the HOPE survey. For Fanning the strengths of this definition are that it does not reduce spirituality to 'an essentially emotive phenomena", or "to [a]codified or institutionalized belief" (Fanning, 2016, p.105). As well, it opens an HCP to recognize that spirituality is complex and can be expressed in many ways. However, Fanning acknowledges that this definition also has its shortcomings. For one, the proposed relationship between cognition, emotion, and behavior implies a spirituality that is cyclical, as beliefs influence emotional states and vice versa, oversimplifying the relationship between the two dimensions. Similarly, it connotes that "experiential and emotional aspects of spirituality produce a set of feelings" rather than focusing on normative categories such as dispositions and attitudes that Fanning deems to be more accurate (Fanning, 2016, p.106). Lastly, Fanning critiques Anandarajah and Hight's definition because it is dependent on the existence of certain features, whereas Fanning asserts that "Spirituality is also the realm where these same attitudes, emotions, and behaviors can be absent or hindered" (Fanning, 2016, p.107).

As an alternative, Fanning advocates for Daniel Sheridan's definition of spirituality which is understood as "a mode of culture in which the human being transforms the problematic of the human predicament immanently within the plenum and spectrum of human resources in time and space" (Fanning, 2016, p.107). In this way, culture plays the role which society often attributes to religion. So rather than religion being a species of the genus spirituality, they are both within the genus of culture, and religion is spirituality with a theistic concern. Sheridan's definition, according to Fanning (and I would have to agree) helps to justify the similar use of spirituality in medical literature where it is a general cultural phenomenon and religion a more specific one. The question then becomes; how does this particular definition improve the conversation between HCP's and patients? Fanning proposes that instead of a formal assessment, the HCP should look for spirituality by examining the "intentional stances of patients that transform the limiting conditions of their knowing (e.g., cognitive uncertainty), doing (e.g., practical/moral uncertainty) and being (constraints of embodiment)" (Fanning, 2016, p.108). One must recognize then that these intentional stances are movements bound within the history and society of a culture but not completely in line with them. Therefore in a pluralistic society, it is not surprising that Fanning does not want HCPs to be surprised when patients exhibit these modes of culture.

Like Fanning, in "A Qualitative Look into Israeli genetic Experts' Insights Regarding Culturally Competent Genetic Counseling and Recommendations for Its Enhancement", the inclusion of religion is defined within the bounds of cultural competency in genetic counseling. For them, religious beliefs are evidently part of cultural background and therefore impact perceptions of science and genetics specifically (Siani and Ben-Zvi Assaraf, 2017). In this article, religion is referred to as "cultural/religious characteristics" which is one of three categories important to their discussion of cultural competency in genetic counseling, the other two being " genetic education" and "geographic location" (Siani and Ben-Zvi Assaraf , 2017, p.1261). It is also listed specifically as that which makes culturally competent genetic counseling important (Siani and Ben-Zvi Assaraf, 2017). Part of the authors' argument for the importance of culturally competent genetic counseling includes discussing religion as a possible "barrier" grouped in with all other cultural barriers to understanding and decision-making within genetic counseling (Siani and Ben-Zvi Assaraf , 2017, p.1264). For the authors “Counselees have the right to make choices based on their own perceptions and values, and counselors must therefore understand what these are, respect them as legitimate, and take them into account” (Siani and Ben-Zvi Assaraf, 2017, p. 1265). Religion affects these perceptions and is part of these values. It is important to note that this article was written in the Israeli context which, like the US or Canada, is a multi-cultural society, making the recommendations and/or the contextualization of religion within culture possibly more generalizable. However, Israel also has more evident structural religious leanings which may increase the visibility and engagement of religion within society generally, and genetic counseling specifically.

In “Religion, Spirituality, and Genetics: Mapping the Terrain for Research Purposes”, the author asserts that the way in which we define religion and spirituality in genetics is very important (Churchill 2009). Failure to address R/S misses an important domain that can lead to misunderstandings. Churchill describes himself as a “student of religion” though he might be defining this as a personal interest rather than as a researcher in the field of religious studies (Churchill, 2009, p.8). However, his interest does provide him with a broad view of the significance of religion and spirituality in the context of genetic research. Even though he says that the academic study of religion has tried to “de-Christianize” and de-theologize” religion in order for it to be studied as a human phenomenon, it has not prevented a more widespread use of the term spirituality in lieu of religion (Churchill, 2009, p. 8). For him, humanities and social science research must “reflect current cultural usage in order to avoid misunderstanding, and to capture those experiences of deep significance to doctors and patients who would not consider themselves religious” (Churchill, 2009, p.8). In light of this, Churchill asks “How does R/S come into play, and what jobs does it perform?” because in the clinical context the most important factor is to understand how religion and spirituality affect perceptions and decisions (Churchill, 2009, p.9).

Churchill focuses on a non-normative, functional, and broad definition of R/S wherein essentially the patient and HCP name their terms. However, “the interpretation and use of these data by researchers will always be in the service of some normative goal, such as improved communication with or care for patients with genetic illnesses. Distinguishing between the descriptive process of data-gathering and the normative uses of the findings is, I believe, easier when a broad and functional definition is in play" (Churchill, 2009, p.9). At the very least, for Churchill R/S provides a framework for dealing with fundamental human questions that are both personal and communal. Therefore, studying both genetics and R/S is asking questions at the intersection of two powerful interpretive schemes for understanding the self and the world (Churchill, 2009). The most unique contribution that Churchill makes to the definition of R/S in the genetic or medical context is that he implores us to recognize that one of the defining features of R/S is that it is ineffable and beyond language, therefore we must recognize novel forms of R/S as well as traditional ones (Churchill, 2009). We must recognize that it is impossible to achieve complete transparency over our own deep convictions and attitudes and that they manifest themselves in complex and diverse ways.

2.8 Note: Gaps in Literature

There are still many gaps in the literature specifically pertaining to genetic counseling. Literature that would have been helpful includes qualitative studies with patients on their views of R/S in genetic counseling, interview-based studies on genetic counselors comfort discussing R/S, any literature referencing the place of genetic counseling in the Canadian healthcare system, any literature directly on the relationship of genetic counseling and spiritual care, and any work specifically on the benefit of the integration of religion and spirituality in genetic counseling other than the White article.

Chapter 3: Development of the project and methodology

3.1 Development of the Project

Religious beliefs and practices of patients are significant factors in coping with serious illness, making ethical decisions about treatment options and in decisions about end-of-life care (Puchalski, 2001; Post et al, 2000). While there has been a growing body of research and discussion of the role of spirituality and religion in other medical fields including family medicine (Koenig, 2000), there has only been cursory research on how genetic counselors address the role of religion and spirituality and practice in their counseling work. Considering the importance of genetic information and its impact on many facets of people's lives, including reproduction and aging, spiritual matters may be particularly pertinent.

Genetic counseling aims to provide non-directional and client-centered counseling to patients who either need or have received genetic testing in order to communicate sensitive, uncertain, and technically complicated genetic information to the patient (Weil, 2003). In the existing literature the term spirituality is most often used in order to refer to more idiosyncratic sets of beliefs and personal value sets in patients rather than the established beliefs and practices more directly linked to affiliation with an organized religious tradition (McCormick, 2014; Puchalski et al. 2014). McCormick notes that while general spiritual concerns can be in the purview of the physician, patients with specific religious or doctrinal concerns may need to be referred to a chaplain competent in pastoral care (2014).

This thesis explores how genetic counselors address the spiritual facets of the client: 1) How they recognize and contend with their own spiritual or religious beliefs or lack thereof; 2) the training they received about spirituality and religion; and 3) how they incorporate the spiritual practices or beliefs of the client into their practice and beliefs about genetics. To investigate these questions, I interviewed genetic counselors about their genetic counseling practice and how they may, or may not, address patients' spiritual concerns. By practice, I refer to the clinical practice of genetic counselors which encompasses both the dissemination of scientific genetic information to the client but also psychosocial--"emotional, cognitive, moral, family and social lives"-- recognition of the patient as a whole person (Weil 2003, Doyle et al. 2016). My interest in the topic arose through reading studies on religious views of genetics

(Nelson, 1994, Anderson 2009) as well as research on the connection between spiritual belief and illness experience (Ehman et al.1999; Koenig, 2000; Larson and Larson 2003).

I was interested in learning how genetic counselors view addressing spirituality and religion in their work; whether genetic counselors do in fact bring up spiritual concerns of the patient; how a genetic counselor's personal religious or spiritual views affect how and whether they do address spiritual concerns with their clients; whether genetic counselors view spirituality as particularly pertinent to genetic counseling; and, if they do bring up spiritual concerns, how do they go about it? These general questions are explored in relation to the larger context of the study below in Figure A on page 37. These chapters are then followed by the conclusion.

3.2 Methods

3.2a Recruitment and ethics

Recruitment was conducted via email. It was done through cold emailing departments of genetics and universities and hospitals, as well as through the assistance of a genetic counselor in the field, and through the Canadian Association of Genetic Counselors (CAGC) listery (which costs $50 for a notice to be sent out). The genetic counselor reached out to former students and other connections in the genetic counseling community on my behalf, forwarding a message of invitation from me as well as a consent form which further outlined the study and the role of the participant. My recruitment process admits to significant selection bias, in that my respondents were individuals who were most likely already interested in and/or had already given my research topic some thought and were willing to participate in an interview about the subject.

The inclusion criteria were that each participant had to operate within the Canadian context and had to have been actively practicing in the last five years (though they did not have to have been practicing for five years or more), were an English-speaking genetic counselor who has a MSc. in genetic counseling, and a member of one or more of the genetic counseling professional orders such as Canadian Association of Genetic Counselors (CAGC), American Board of Genetic Counseling (ABGC), Canadian Board of Genetic Counseling (CBGC), and the American Association of Genetic Counselors (AAGC). Participants were also required to provide verbal consent after receiving the consent form and before beginning the participation. My exclusion criteria therefore were genetic counselors who have not practiced within the last five years or who practiced outside of Canada (although I did not recruit outside Canada) and those who were unwilling to provide verbal consent before the initial interview. In my recruitment, I aimed to get respondents in a variety of regions across Canada. I aimed for a sample size of between 10 and 15 due to the qualitative nature of my study as well as the research time constraints of a Master's thesis. Given the size of the Canadian genetic counselor population, 10 to 15 interviews, spread across Canada, should provide me with theoretical saturation (McCallister, 2001).

After a successful recruitment was completed in August of 2021, I had interviewed 13 participants spread out over four provinces: Quebec (four respondents), Ontario (four respondents), British Columbia (two respondents), and Alberta (three respondents). While I will not be disclosing specific cities out of confidentiality concerns due in part to the small size of the genetic counseling community, all respondents work in a city with a population of over 130,000. Twelve of my interviewees identified as women and one as a man. Given the overwhelming majority of women in the genetic counseling, this gender disparity seems to be consistent with the overall demographic range in the field (Abacans et. Al, 2019) (Stern, 2012), (Reis et. al, 2007).

My consent form included a summary of the project as well as information on the conditions of participation. Participants were able to withdraw consent at any time. Participants were also made aware that all personal information would be de-identified, pseudonyms would be used, and any data would only be used for the purpose of this thesis and any identifying information would be kept solely on a password protected personal computer in a password protected hard file form. No data was stored in any sort of cloud system. This study received ethics approval from the IRB at the McGill University Faculty of Medicine and Health Sciences on June 6, 2021 before the start of any interviews.

3.2b Interview Process:

I conducted a qualitative study, using a semi-structured interview approach. A clear set of questions were prepared and asked in each interview, however there was room for participants to expand on their answers and for the interviewer to ask further related questions and follow what the respondent deemed their most pertinent concerns on the topic (Kailio et al. 2016; McCallister, 2001). I developed the set of questions (interview guide) based on preliminary readings I found using keyword searches both though the McGill Library system and Google Scholar. The keywords I used were genetic counseling/counselor, religion, spirituality, and genetic counseling practice. The original interview guide was used for my pilot interview with my first participant who was aware of the fact that this was my pilot interview. After the pilot interview, I revised the interview guide according to what was missing from the results of this interview (Kailio et al. 2016). This included important demographic information on years of experience and context of the specific area of practice of the participant. No further changes were made after any of the subsequent interviews. However, given the semi-structured nature of the interview process, questions for elaboration were spontaneously added in between the questions listed on the interview guide if clarification was necessary. The interview guide ended up containing a total of 21 questions ranging from demographic information to the personal religious or spiritual affiliations or stances of the participants and how that affects their practice. These questions can be found in Appendix A on page 80.

Thirteen interviews were conducted between July 7, 2021 and September 9, 2021. Each interview took place through Zoom or over the phone and was recorded using either the Zoom system and downloaded to my private computer or recorded using voice memo on my private computer while on speaker phone. For each interview I (the researcher) was in a private space where none of the interview content could be overheard. The duration of the interviews ranged from 15 minutes to 40 minutes depending on the input of the respondent.

Note on language: In the interviews I used both the terms religion and spirituality and allowed participants to self-define or identify with either, to get a broader range of responses given the broad range of experiences associated with both.

3.2c Bias in interviewing

Before beginning my interview process, I conducted a small literature survey on the topic to enable me to prepare my interview guide. The literature survey was purposefully small in order to reduce bias in my interview practice, by reducing the knowledge I had which could influence my expectations for particular responses. However, throughout the interview process and subsequent analysis, I was aware of my bias as someone with a Religious Studies background. This disciplinary perspective means I tend to come to research scenarios with an expectation that religion or spirituality will play an important role for the participants. However, the goal in this study was to determine whether that is in fact true in genetic counseling. In order to reduce the effect of my bias in the context of the interviews I did not discuss my academic background other than what was already in the consent form (found in Appendix B, p.82) before the start of the interview. As well, when I asked questions outside of those in the interview guide, I made sure to use language that the participant had already heard in previous questions or used in previous answers so as to not put words in the participants' mouth.

3.2d Analysis

Analysis of the interview transcripts was done through an inductive coding method using Microsoft Word and the software NVivo. NVivo is a qualitative research analysis software that allows you to gather all your data in one place and extrapolate themes through coding of data. In the context of qualitative data analysis a code "is most often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data." (Saldana, 2008, p. 3) Coding is then assigning these words and short phrases to all of your data, although more and different codes will become apparent as you repeatedly go over the data, you are then codifying your data throughout this cyclical analysis (Saldana, 2008). As the process goes on, categories will emerge out of the codes and some codes will be filed under these categories (parent code) as sub codes (child code). Through both codes and categories, data is linked together allowing overarching themes and questions to become more apparent (Saldana, 2008). In this case I began thinking about coding the interviews when transcription started. While transcribing I annotated the interviews line by line to begin to draw out emerging codes and connections among the separate interviews. The notations were originally done in Word by using the review function and adding comments. After this was done for all of the interviews, I then obtained the NVivo software and uploaded all of my files there.

In NVivo, I began creating codes in reference to my previously written notes on the original transcripts. I utilized a grounded approach (looking for themes from the bottom up rather than top down) and used inductive thematic coding to extract themes from the interviews (Bryant and Charmaz, 2019). I then coded my interviews manually in NVivo. Because much of the work had been done ahead, in the transcription stage as I was listening to the interviews, I was able to simultaneously code both descriptively and analytically once this data was inputted in NVivo. During the coding process, some codes became subordinate to other codes and new codes were continuously being created. In total, I ended up with 20 parent codes and 10 child or subordinate codes which I then arranged in a map in order to draw further connections as seen below in Figure B.

Each interview was created as a case which then enabled me to classify each interview by certain demographic information. These classifications were province and years of experience. Years of experience was then divided between those who had practiced for less than five years and those who had practiced for more than five years. However, given the small sample size, these characteristics were not particularly illuminating categories. The results and discussion are split into three chapters per the coding structures post analysis (see Figure B below on page 38):

1. Goals of Genetic counseling: What do the participants mention as the goals of their profession both generally and personally and how does religion and spirituality play a role.
2. Genetic counselors' personal beliefs and how they relate to their practice
3. Resource Availability/ Management in regard to religion and spirituality in genetic counseling

My sample size prohibits me from drawing far-reaching conclusions from my data; however, the information gleaned allows me to make suggestions for further research and resources in reference to spirituality in relation to the practice of genetic counseling. The results are mostly descriptive but understood through an analytic lens. Given that there are ~270 practicing genetic counselors in Canada (Albacans, 2019) my sample size of 13 offers a view of about 1/20th of the population. This can be seen in the coding structure diagram in Figure B wherein there are overarching themes that then connect to different parent and child codes. The parent and child also sometimes fit under multiple themes linking the themes together. I then compared the emerging themes with existing literature (Vaismorandi et al. 2016; McCallister, 2001) to make the aforementioned recommendations for further research as well as to discuss further tools and resources that genetic counselors could use in the results section as well as conclusion.

3.2e Bias in Analysis (validation and reliability)

During the coding of the interview transcripts, I was aware that all of the codes were generated in light of my particular perspective and background. Therefore, it is important to detail that background in describing the analysis of the data. I was raised in a white, upper-middle class family in coastal Massachusetts. I then moved to Montreal in 2015 to attend McGill University. In 2019 I received a Bachelor of Arts in Religious Studies with a minor in the Social Studies of Medicine. This thesis was then completed in the course of a Masters of Arts in Religious Studies with a specialization in Bioethics. All this to say my interest lies in how religion and spirituality affect and is addressed in the medical context both now and historically. Thus in my development of this study and in its analysis, I was aware that I may be making assumptions about the importance of spirituality and religion in any given context. As well, my racial and socio-economic background do not include a lot of references for hardship with regard to either health or finances. While I remained aware of these biases during data gathering and analysis there is no approach to achieve full objectivity, nor was I aiming to, as my interests and point of views are what initially instigated this project and enriched the analysis.

Figure A:

How do genetic counselors view the addressing religion and spirituality in their work?

How do a genetic counselor's personal religious or spiritual views affect how and whether they do address the religious and spiritual cncerns of clients?

If/when genetic counselors do bring up spiritualor religious concerns, how do they go about it?

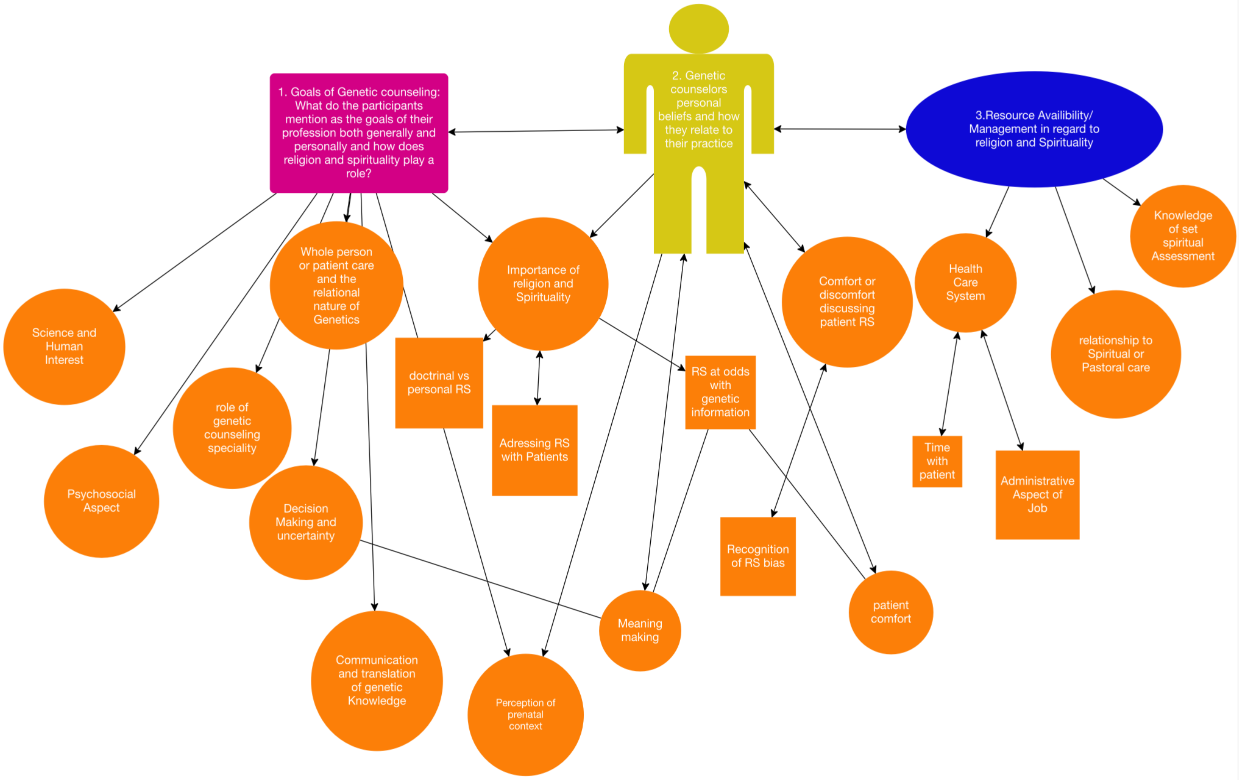
My research will explore how genetic counselors specifically address the spiritual and religious facets of the patient, and how recognition of the spiritual practices or beliefs of the patient pertains to treatment of the whole person in regard to genetic counseling.

Do genetic counselors in fact bring up the spiritual or religious concerns of the patient?

Do genetic counselors view spirituality as particularly pertinent to genetic counselling?

How do genetic couselors conceptualize caring for the whole person and does that include spiritual or religious concerns?

Figure B


1. Goals of Genetic counseling: What do the participants mention as the goals of their profession both generally and personally and how does religion and spirituality play a role?
2. Genetic counselors personal beliefs and how they relate to their practice
3.Resource Availibility/ Management in regard to religion and Spirituality
Science and Human Interest
Psychosocial Aspect
role of genetic counseling speciality
Whole person or patient care and the relational nature of Genetics
Decision Making and uncertainty
Communication and translation of genetic Knowledge
doctrinal vs personal RS
Importance of religion and Spirituality
Adressing RS with Patients
Perception of prenatal context
Meaning making
RS at odds with genetic information
Recognition of RS bias
Comfort or discomfort discussing patient RS
patient comfort
Health Care System
Time with patient
Administrative Aspect of Job
relationship to Spiritual or Pastoral care
Knowledge of set spiritual Assessment

Chapter 4: Goals of Genetic counseling; What do participants mention as the goals of their profession, and how does religion and spirituality play a role?

Study participants offered varying views of what they saw as their role in the medical system and of their duty to their clients. B.B. Biesecker summarizes the current psychoeducational paradigm in genetic counseling as “promoting understanding, achieving informed consent, facilitating decision-making, reducing psychological distress, restoring feelings of personal control, and advancing adaptation to stress-inducing events” (Biesecker, 2001, p. 327). This serves as a general referent definition of what the goal of genetic counseling is. While the answers the respondents gave in this study were varied, they all encompassed similar themes around communication and translation of genetic knowledge and aiding clients to make decisions. Religion and spirituality entered into the interview dialogue through direct questions about its influence on the participants’ practice. The main themes that arose were the importance of the genetic counseling specialty (often mentioning the prenatal context); the psychosocial aspects of practice; the uncertainty inherent in genetic testing and diagnosis; and the role of religion and spirituality in the decision making process in genetic counseling. The term whole person or patient care was then also addressed through direct questioning as seen in the interview guide in Appendix A (p. 80).

4.1 Communication and translation of genetic knowledge: the basics

Genetic counseling is performed in many different medical contexts: general, pediatric, neurological, and pre-natal, to name only a few. At the most basic level in all contexts, genetic counseling’s main goal is the communication and translation of complicated genetic information regarding heredity, testing, and diagnosis. This base aspect was mentioned directly in 11 of the 13 interviews in this study. For example, Katey stated:

> And then there's a big part of our job that is explaining genetic testing, facilitating genetic testing, helping the patient to make an informed decision about whether genetic testing is right for them. And then when those results come back, explaining those results, and making the information accessible to patients (Katey).

As she says, making information accessible to patients is a large part of the goal of genetic counseling. When information is accessible, patients can be more informed in their decision-making process for genetic testing as well as lifestyle choices in regard to diagnostic information and risk factors. Genetic counselors make information accessible to clients through many practices, but in order to know what information will be most pertinent to a client, the genetic counselor must understand the needs and perspectives of the individual client. Wade makes the point that:

> I guess I feel genetic counseling is more than just giving information. But truly, I think that's where the counseling aspect of genetic counseling is so important is that it's not only giving that information, but working with that information to allow the individual to adapt from their particular whole perspective, right (Wade).

Coming to an understanding of the clients' perspective as Wade mentions is often done through the psychosocial counseling paradigm (Weil, 2000).

While there are no standardized tools that all counselors use, almost all genetic counseling begins with gathering a family history which evaluates both medical and social information as well as psychological insights into the client (Djurdjinovic 2009; Weil, 2000). Within the psychosocial paradigm, genetic counselors are also taught to practice "attuned listening" in order to learn the client's story, asking questions such as "what brings them to genetic counseling?" (Djurdjinovic, 2009, p.136). Holly puts this particularly well when she says:

> My favorite one and the one that's like the most genetic counseling is meeting patients. Sometimes there's a specific genetic test I would like to offer them based on their medical history of family history. So collecting some of that information, and then discussing the test kind of going through informed consent. Speaking with the patient about how that testing fits into their lives, what it can tell them what it can't tell them, preparing them for results, when results come back, you know, going through them what it means the inheritance pattern, the risks to other family members, what's the chance of this condition, if it has a genetic cause, what could happen, if it could happen to someone else in the family, what those risks are, what the testing options are (Holly).

So genetic counseling is more than just the communication and translation of complicated genetic information because in order to help the client understand that information, the clinician must come understand who the client is, from meeting them through to diagnosis, if diagnosis is necessary or possible. The specific phrase “psychosocial” was not spoken very often in the interview process despite it being a core concept within the genetic training literature as seen in *A Guide to Genetic Counseling* (Uhlmann et. al, 2009), the Genetic Counseling Practice based Competencies (Doyle et. al, 2016), and *Facilitating the Genetic Counseling Process* (McCarthy Veach et. al, 2018*)* (the most recent textbook I was able to find). In *Facilitating the Genetic Counseling Process* however, the psychosocial paradigm is mentioned as a given within other counseling paradigms such as the “reciprocal engagement model of practice” (McCarthy Veach et. al, 2018, p.33). When the term psychosocial was mentioned directly in interview it was presented as the main goal or tenant of the individuals genetic counseling practice:

> Quote 1: Yeah, so just generally, I would describe a genetic counselor as a healthcare professional who works in either a hospital or another kind of medical setting, and works with patients to help them to adapt to some of those psychosocial issues that come about with a genetic diagnosis or having a family member with a genetic diagnosis (Katey).
>
> Quote 2: And so I see patients in the clinic, I do everything except prenatal and cancer and to provide counseling, which should include doing a risk assessment, medical history, family history, informing them about the genetic condition in question explaining genetics to them, helping offering testing, helping them understand benefits, limitations, possible results in testing, and then disclosing those results, helping them adjust to those results. And with psychosocial counseling, intermingle all three of that (Doreen).

While Katey uses the term psychosocial as a descriptor for “issues” that a client may encounter during the counseling process, Doreen uses it in the sense of the counseling practice paradigm. However, Katey also understands the term in the sense of a practice paradigm, saying:

> Often as a genetic counselor [one] will…one of the tools in our toolbox, psychosocial toolbox is assessing what supports the patient has. So in practice, one way that would come out is if someone's like, really upset or like struggling with a diagnosis, sometimes I'll ask like, oh, are there other supports in your life? Or is there someone that you talk to about things like this? And I think religion definitely plays religion and spiritual spirituality plays a role in that support (Katey).

As evidenced above, the psychosocial paradigm is important to this project as it is where R/S comes into the genetic counseling equation in that psychosocial counseling practice delves into the support system of the client as well as acknowledging the client as a person with many different aspects including R/S.

4.2 Importance of Religion and Spirituality in Genetic Counseling

A major question I had during study development as well as during the interview process for this is study, is whether R/S is in fact important or useful to the genetic counseling process for the client? Answers to this were mixed. However, there were enough connections made that it certainly warrants further discussion. Given that questions in the interview process directly asked about R/S there was no variability in whether it would be brought up. I created two categories to analyze years of experience: (1) those who had practiced for less than 5 years and (2) those who had practiced for more than five years. Length of practice significantly affected the number of cases the practitioner had seen as well as the number of genetic counseling contexts they had worked in, and thus their chance for exposure to spirituality and religion in their practice. As seen in the last quote from Katey, it was deemed possibly important with regard to support systems for clients.

R/S was also heavily referenced regarding decision-making, acknowledging the values of the client, and coping with difficult news. As Rebecca says:

> For those whom religion is an important aspect of their lives, I think it is really critical to acknowledge that, because it shows that, you know, we respect them as an individual in terms of what their values are, what priorities they're taking into consideration when making decisions about their medical care, or about their reproductive future, or, you know, whatever other aspects of their lives (Rebecca).

Wade makes similarly important point about the centrality of belief if it is important to a client:

> So if someone does have a belief system that is important to them, it's usually very central to them as well. And so, if you're not at addressing, like, you know, I don't know if you know, in terms of, you know, when you look at counseling on a whole, you know, you're looking at the whole person, you know, their physical, their spiritual, their psychological, all of those aspects, I kind of talk about kind of spokes on a wheel. And in

> order for your journey to go smoothly, those spokes have to be kind of all working in conjunction with, with each other for that real wheel to roll well (Wade).

In this case, Wade sees the importance of addressing belief systems as a way to help clients continue on smoothly.

In "Making Sense of Genetic Uncertainty: The Role of Religion and Spirituality," M. T. White (2009) argues that the utility of R/S comes into play with the uncertainty and risk that is inherent in genetic medicine, "Genetic testing thus raises existential questions about a person's biological identity that may have profound implications for the person's sense of security, confidence in his or her physical health and reproductive capacities, and may link the person directly with his or her mortality"(White, 2009, p.69). Spirituality within the medical context is connected through these questions of mortality and uncertainty that bring up questions of the future and ultimately meaning (Churchill, 2009; Fanning, 2016; Fanning and Clayton, 2009; White, 2009; Murray et al. 2020). White concludes that "[i]n the context of genetic counseling, religious and spiritual values are regarded essentially as heuristics that may assist some clients in coping with their genetic risks" (Murray et. al, 2020, p.75). However, she tempers this assertion by saying that discussions of spirituality should be limited to how R/S may influence interpretations of risk and decision making. Gloria echoes this in her interpretation of spirituality as it pertains to her practice a genetic counselor:

> In terms of spirituality, right, like, I don't know how you want to define spirituality, but I do a lot of predictives and predictives mean, you know, we found a gene in the family and now these asymptomatic family members have come to me and they want to know whether they have the gene and then, will they develop the disease early on in their life. And it's a disease that's neurodegenerative, no prevention, no treatments, the knowledge of knowing really is just to, to prepare themselves emotionally and psychologically or financially. And so I do bring in the topic of the concept of death, or the meaning of life and purpose of life. So if you want to look at spirituality in that sense, you know, I talk about it quite a bit, in a religious sense, very little (Gloria).

Fanning (2016) problematizes the use of R/S in genetic counseling practice by arguing that even if it is important to clients, the dangers of bringing it up without cues from the client may outweigh the benefits. In the interviews for this study many participants also responded that the study itself was thought provoking and that it was perhaps something they should consider more in their work, demonstrating that it is indeed an issue warranting more consideration. No interviewee responded that they would not address it at all or thought it was ultimately harmful.

4.3 Genetic Counseling Specialty

The genetic counselor's specific specialty was often cited as a determining factor in whether R/S was addressed or considered. While none of the participants thought it would bring about great harm to their clients it was often remarked that: It doesn't come up as much as maybe I thought it would (Holly). However, she then remarks, "It might be related to kind of my area that I work in right now, which is mostly general, and metabolics" (Holly). Similarly, Gloria pointed out that while every genetic counselor gets relatively the same training (Murray et al. 2020), in actual practice there is large variance in what comes up depending on context:

> I'm just thinking, you know, we're all trained in the same background, right. But then, depending on the clinic, some clinics are very general and other clinics are very specialized. So you know, when I saw [this] study, I'm like, I, I'm just thinking back to my practice, and I barely had any conversations about spirituality or beliefs (Gloria).

It is important to note that the participants saw R/S as having the greatest utility in the prenatal genetic setting due to considerations of pregnancy termination. The correlation between the prenatal context and issues of R/S is already supported by the existing literature: the genetics literature that addresses R/S is largely focused on prenatal genetic counseling (Anderson, 2009; Sagaser et al. 2016; Nelson, 1994). For example Susan pointed out that:

> I think the biggest role that it plays would be in family planning for a lot of people. It also I mean, sometimes, when it comes to, like, finding out what the diagnosis is, sometimes people kind of go well, 'they are who they are, what will a diagnosis change for that?' And so I think, in decision making, for the families, it can be, it can be a huge factor (Susan).

Doreen also agrees and stated during the interview that it was difficult to think about addressing R/S with patients outside the prenatal setting:

> Again, this is all kind of a try to think of outside of the prenatal setting, but it really doesn't come up for me anyway. So the prenatal setting, the times that I referred, are where people are really struggling with decision making. Usually surrounding continuing

> or ending a pregnancy and so they may or may not already have their own supports from their own religious institutions (Doreen).

She also makes an important point that will be addressed in the future, that even in the prenatal setting, clients may have R/S support already accessible to them in their existing community. Rebecca R. Anderson, in an oft-cited article on different faith's attitudes towards the termination of pregnancy that is also often used in genetic counseling training literature, makes the point that "[f]aith-based approaches to decision-making may not seem consonant with the cognitive-behavioral paradigm of contemporary counseling which emphasizes personal locus of control and models affirmative imagery." Decision-making in "God's name" may be seen to undermine autonomy and self-determination (Anderson, 2009, p. 52). However, the study was mostly practical rather than theoretical in that it surveyed specific US religious denominations to provide doctrinal responses and resources in response to prenatal genetics. This is helpful as a guideline but does not really help practitioners understand how to broach the subject with clients. As well, in most interviews with genetic counselors in this study the majority of respondents felt that clients were referencing a personal spirituality rather than organized religion:

> Yeah, I'm thinking back to the examples that come to mind, are the cases where somebody is considering termination of a pregnancy. And in those cases, where I've had several people say, oh I can't… like either something spiritually, or something that they can't like choose, they don't feel that they can do. And even the people that tell me that it's against their religion . . . what I explore, you know, what that means, and what that looks like, they often… it's more of their own personal beliefs rather than the, the outside pressures, or like this feeling like worried that they're going to be judged or, or kind of acting against (Shelley).

4.4 Addressing R/S with clients: practical questions

The great majority of respondents stated that they waited for the client to bring up R/S rather than asking direct questions to the client. The exception here is when taking a family history wherein religions with particular gene pools need to be identified due to proclivities to particularly genetic diseases such as Ashkenazi Jews:

> I generally wait for them to bring it up. Sometimes we'll end up having a little bit more of an involved discussion that I initiate, particularly in the case of if we're asking about

> Ashkenazi Jewish ancestry, because some people are confused why we asked about a very specific religion. And so that sort of spurs on a discussion that like, well, it's not so much the religious aspect that we're interested in this particular point in time with this question and more about sort of the history and the, the idea of Ashkenazi Jews as a kind of distinct ethnic group that has typically intermarried within itself, meaning there's conditions that are more common within that community. But past that, sort of, like academic discussion of why we ask that question, in terms of the influence of religion, or spirituality in a patient's life itself, typically I wait for the patient to bring it up (Rebecca).

The literature supports this in that almost all studies that interviewed or surveyed genetic counselors found that they were most comfortable and most likely to bring up R/S with clients if the clients brought it up first or used religious or spiritual vocabulary in conversation (Reis et al. 2007; Sagaser et al, 2016). Gloria reflects this well when she says she addresses R/S with clients by responding to their way of communicating:

> I acknowledge their beliefs. And I just build up on it. And you know, if I see an opportunity later on the conversation, I'll use with the words that they've said and take it back or, you know, all I'll just give the example with the guy where he believed in God right. You know, I let him speak, to speak. And then you know, at a later time, I just brought in that concept of God to kind of reiterate what I was trying to, or reiterate the idea that I was trying to emphasize and, and you something that he can relate to. So it's all about relating their beliefs to our basic science concepts (Gloria).

Listening to and mirroring clients' language is a major part of the psychosocial and client-centered paradigm that is central to the educational literature for genetic counselors. But what if clients do not bring up R/S? During the interviews many participants expressed that after participating they saw the benefit of perhaps asking clients directly even if they do not bring it up which is supported statistically by the surveys in Reis et al. (2007), and Sagaser et al. (2016) and theoretically by the work of Koenig (2000), Puchalski (2014), and Larson and Larson (2003).

4.5 Decision Making and Uncertainty: Meaning making

The theoretical literature describes the utility of R/S in genetic counseling for decision making in the face of uncertainty, and, moreover, in the meaning making attached to these processes (Baty, 2009; White, 2009; Koenig, 2000; Puchalski, 2014). Genetic counseling may bring up difficult questions surrounding the future, health, and relationships of clients which requires different "heuristics" (White, 2009) to create make meaning in the face of suffering and difficulty. R/S is one of these heuristics, seen as a way of explaining and making sense of the world which contributes to dealing with, making decisions about, and the meaning making, surrounding difficult medical information. Respondents supported this view:

> Quote 1: It's very important. It's important because that's how they want to shape their life and make their like… the decisions that people are making are huge life decisions, life changing, life altering decisions. So anytime I think a patient or anybody, anytime anybody makes a big life altering decision if they are faith-filled, or religious people they will often use their faith or religion to, you know, as a guide. So, because it's a way of life, right, so it's not just, it's not just a demographic, it's how it's how you think it's how you react, it's how you see the world, it's how you make decisions (Raphaelle).
>
> Quote 2: And what it is that her like, you know, they're looking for guidance on what it is to do. Right. So I feel that the decision a person makes goes beyond just talking about a particular diagnosis, I guess (Beth).
>
> Quote 3: I just ask them all I just let them know that exactly what I was describing, the decision to be tested, could have significance in other parts of your life, right? [implied: e.g. R/S, family, relationships, etc.] It's not [just] about risks. And then I would highlight different things and ask them about: Have you talked to other people you know? Do you think this is something that would be easier, easy to do or would not be easy to do? [Do] You know, anybody in your social group has undergone this you know, anybody who has even tested ? How do you imagine doing this? Do you think you're able to do this? Right? What are the most important things to you? Not just saying okay, we'll remove the risks and goodbye, we're screening the risk and Goodbye! (Beth)

The last quote from Beth outlines that not only does she look into how a decision about genetic testing or diagnosis affects the individual but also that it can affect other significant things and relationships in their life. This is true whether it be family or religious community. Genetics is a very particular medical context that includes much more uncertainty than most (White, 2009), both diagnostically and for risk management in the face of gene identification. This is especially pertinent in that many of these diseases have long timelines with lots of uncertainty, so clients are going to need tools to place their diagnosis within their life and worldview for a very long time. As Wade notes:

> And dealing with uncertainty, sometimes too, that's another big piece, because we don't know everything. And we don't pretend to know everything, because we don't. And so sometimes you're saying, 'We don't know what this is gonna look like down the road. And, you know, it could be this, it could be this. We can do some testing to clarify this. But at the end of the day, it might not give us an answer.' And, yeah, and trying to, you know, then live with that uncertainty, because many people do want kind of black and white answers, it's easier to make decisions if you have a black and white answer, but it's much harder if it's just this. Not sure what this is, not sure what's going on here. We can, you know, we can try to find out, but we may not. So, yeah. All part of genetic counseling (Wade).

Genetic counseling very often cannot provide black and white answers that make decision-making or everyday life easy, therefore clients often need other "heuristics" as White says to help in the coping and decision-making process such as R/S, White explains:

> Because religious and spiritual influences are so personal, so diverse, and in genetic decision-making seem to serve chiefly to bring meaning to uncertainty, they may be understood essentially as a heuristic strategy, as one more interpretive framework that may help some people move forward in the face of overwhelming or unintelligible circumstances (White, 2009, p.73).

As seen in the above two quote sections, genetic counselors saw R/S as a way of interpreting both the immediate and ongoing suffering of serious illness that may be even more pertinent in genetic illness and genetic counseling given the uncertainty and longevity of genetic illness.

How then, might acknowledging R/S in genetic counseling contribute to quality of life for clients? In her chapter “Embodied Practices for Healing and Wholeness”, Meredith McGuire (2008) discusses the recent historical division between religion and health, arguing that this division dates back only two centuries at most. It is not surprising, then, that many of her respondents in her interview-based study “considered physical and emotional health, spiritual depth and growth, and sense of well-being to be intertwined in an adamantly holistic linkage of mind, body, and spirit” (McGuire, 2008, p.120). As well, she points out that there are no universal criteria for health but rather that it varies over time and between cultures (McGuire, 2008). Therefore, the boundaries between and around health and religion are socially constructed.

With the separation of the spheres there is then the danger that the individual with the illness or the “bad” genes will be treated as the illness itself as “disordered bodily functions, such as biochemical or neurophysiological malfunctions” (McGuire, 2008, p.136) rather than a body that has many other social, psychological, spiritual or behavioral elements. Thus, the illness becomes localized in an individual body. Genetics however is inherently relational, in that your genes are something that you share with your biological family. As well, similar to non-genetic medicine, genetic illness requires coping through many different avenues that are also relational, such as R/S, which as McGuire argues, is an inherently human phenomenon that spreads through human channels aka relationships of many sorts (2008). Similarly, Puchalski argues that addressing spiritual concerns in patients (not specifically genetic ones in this case) allows practitioners to address the broader issue of ‘meaning making’ in illness and allows patients to find dignity and purpose in life with illness (Puchalski, 2014, p.8). Many respondents mentioned R/S as a basis for an interpretive structure in their work with clients that then helps with finding alternative pathways to healing:

> It’s like, especially if they're struggling with understanding, like, you know, let's say, after we got tested or something, or even, like, you know, after they got tested, and let's say nothing was found, and that they, they're distraught, like nothing was found, and they're hoping it was genetic. So sometimes we talk about like, what, what do you think caused your cancer, or? So sometimes, spirituality and religious impacts there. And also, especially I find, and coping, and trying to find alternatives, let's see, ways of healing. Mainly where it (R/S) enters in a discussion (Beth).

The healing mentioned is not necessarily a cure from the disease, rather it is the relief of suffering through finding meaning in illness. Wade discusses this in the long term need for coping as well, and the importance of understanding and helping clients stay in touch with their values:

> And so if once you move away from your core beliefs and values, that's when you can run into problems in terms of, you know, even though, you know, terminate, for example, termination of a pregnancy may be an easy thing, in regard to kind of the problem that presents itself, that may have longer term consequences, because it's in direct conflict, maybe some of your beliefs around that, for example, and so, you know, that may have, you know, may not kind of impact immediately, or maybe impact later, or it may cause you to change your belief systems to maybe be more congruent with where you're at, and, and your decision making as well. So, you know, some of these life events are quite life changing for some people as well, where, you know, they haven't had to go through some of these deep waters in their life. And as they're going through these deep waters, they're realizing and reflecting on that, if they're properly kind of addressing these things, as opposed to just burying them, then they sometimes come out of the other side with a very better sense of themselves, and who they are and what is important to them. And that's really spirituality in some ways, in my mind (Wade).

Gloria also sees that learning in a session what is good in life for a client is important to helping them deal with illness and that the conversation can be very spiritual in its reference to meaning making on a long-term level.

> In the work, and in the predictive that I do, I think it is important because it gives them motivation, or it gives them a purpose or allows them to or I think it's, it allows them to not focus on the anxiety part or on the negative part of diseases or negative part of life, you know, you want to focus on the good in life. What is good for that person, you know, what's the meaning of a good life? like I used to work in cancer before. And you know, like amount of times, I would see people towards end of life and have so many regrets in life. So I kind of use that as a grounding, you know, like, kind of like, people, few people have the opportunity to know how they will die. And so why not use that? Like, they have a time to kind of think, you know, I will die in about a span of five to 10 years what do I do in my life that I’m not happy about? (Gloria)

What do they see as their purpose? What do they hope for? These are spiritual questions according to Puchalski (2014),White (2009), Larson and Larson(2003), Churchill (2009) and Koenig (2000), and genetic counseling, wherein the key word is counseling, is uniquely situated to address those questions:

> But truly, I think that's where the counseling aspect of genetic counseling is so important is that it's not only giving that information, but working with that information to allow the individual to adapt from their particular whole perspective, right (Wade).

To allow the client to adapt to information in a sustainable manner, the genetic counselor must be cognizant of the client's particular whole world view and relationships. Per Zuckerman, recognition of this whole world view includes acknowledging that belief systems (R/S) are a part of a client's particular context (2021).

The respondents were asked how they would define the term "whole person or patient care." They were also asked how they would or have embodied it in their work. While many had a response, very few had heard the term directly in reference to their work or had not heard it at all. However, because the term is relatively self-explanatory, almost all respondents were able to provide an answer that was pertinent and addressed the idea of the person alongside the illness. For instance, Andrea stated that

> While reflecting back, certainly we do address kind of the social determinants of health as they pertain to genetics for such a niche field. So I feel sometimes it's harder to like… we just play one kind of specialist role rather than kind of addressing all aspects of health. But in terms of how do I embody that? I would say we are certainly are aware kind of about, we ask questions regarding people's support systems, their beliefs, how they make decisions, that kind of things. So I would say that kind of support or kind of, would be how I embody that. But also, yeah, just kind of exploring just all the avenues and how they, how they impact a person's decision (Andrea).

Notably she expresses that addressing all of these different aspects of the client is difficult when working in such a niche medical field, but references the importance of determining people's support systems through ALL avenues. Similarly, Susan took it to mean seeing the client as "just everything in their life that's kind of added up to this person sitting in front of me right now, whether that's like, support networks, or, you know, past previous experiences and that kind of thing" (Susan). More specifically, Gloria noted that "whole person care is not only in the physical, but also the mental also the psychological, psychological goal, and also the spiritual that comes in" (Gloria). As Puchalski says "Unless the health care practitioner is attentive to all the dimensions of suffering—the psychosocial and spiritual, as well as the physical—the entire focus of care may be on physical pain while neglecting the spiritual or existential distress" (2014, p. 6).

4.6 Conclusion

So the goal of genetic counseling is more than communicating the genetic medical information, more in fact than communicating risk factors or uncertainty in diagnosis. It would be more apt to say that there are goals plural in genetic counseling, including communicating the genetic medical information, testing options, risk factors, and supporting the client through the decision making inherent in those conversations. This support work is where R/S enters the genetic counselling equation. The participants in this study saw R/S as something that should be addressed as part of supporting clients through the harder parts of the genetic counseling process such as decision making and confronting difficult diagnoses, especially if the client brings it up. Addressing R/S in an informed way when necessary can contribute to client healing and allow clients to feel that their worldview is understood and respected in the genetic counseling process.

Chapter 5 : Genetic Counselors Personal Beliefs and How They Relate to Their Practice

So far, I have been addressing the importance of R/S in genetic counseling for the clients of genetic counselors, according to genetic counselors. Now I turn to the R/S values and beliefs of the genetic counselors themselves. In my study only three of the 13 respondents identified as not R/S, or as atheist. The majority of those who identified as R/S identified as spiritual rather than religious, both terms were used in the course of the questions but neither were defined so participants could self-identify as they responded:

> I think, yes, not so much the religion part, the spirituality part, because I do the yoga, I do the deep breathing, you know, the connecting to myself (Gloria)

Here, Gloria identifies herself as spiritual and defines her spirituality through her practices such as yoga, deep breathing and connecting to herself. Alternatively, Raphaelle sees herself as "a faith filled person" and Susan clearly stated "so I identify as atheist." Many participants also responded that they were raised within particular religious traditions and that this had played a role in their thinking surrounding R/S both on a personal and professional level:

> So my history, I grew up from, like a Christian background, my dad was actually a youth pastor until I was 10. I mean, I lived in small-town Saskatchewan, and then we moved to BC. And then we started going to … like more nondenominational churches, like less, less strict, less conservative churches. …And so, I do have a Christian background, but I also have a long history of like being in conflict or resistant to a lot of those things in Christianity. And so that relationship with spirituality, or like Christianity, in my case has matured over time. And, the farther I've gotten out… so I didn't really go to church, post High School, didn't really go to church until I actually did find one that I kind of liked and didn't trigger me so much. And so as, I've gotten more away from it and, read more about Christianity from a more holistic perspective, I appreciate more things about it. There's still certain things that I have soap boxes, and I'm resistant to about for Christianity, but there's a lot more aspects that I appreciate about it, or, I get it a little bit more now, being an adult, and going through some suffering and some pain. I get more things about some of the meaning behind that stuff. So I would say I actually am, like a spiritual person, or … among my peers, I am one of the people who cares more about spiritual concerns, or like Christianity, even among some of my other Christian people in

> my life. So that's my background. Religion, spirituality wise is, you know, gone through rocky relationship. I think a lot of Christians my age probably have, and then kind of come out here (Holly).

Given the variance of personal identification with R/S, the respondents also identified different levels of comfort or discomfort in addressing R/S with patients or clients in relation to their own beliefs, just as Holly references above, sometimes there are “soap boxes” to contend with which is supported by Geller et al. (2009) below. In Wyatt et al.’s (1996) study there was no correlation between personal spirituality in genetic counselors and their comfort or discomfort addressing R/S in their genetic counseling practice. However, another survey (Salamone, 2002) found that those who said they were non-spiritual or non-religious had a lower level of comfort addressing the topic with clients. Reis et al. (2007) also make it clear that genetic counselors often feel most comfortable and/or uncomfortable at all addressing R/S when the client brings it up. Most of my participants originally stated that they were comfortable addressing R/S with clients but when asked whether their personal identification with or not with R/S affected their comfort or discomfort addressing it with their clients, the answers became more complex. Those who identified as religious or spiritual often felt they were more comfortable:

> Absolutely, I think, you know, I just I have more comfort in that whole arena. Just even from talking to my colleagues who don't kind of ask those kind of questions of their patients, because they don't want to open that door because they don't know what's behind that door, and what it will mean for them and, and that they may not be able to provide that kind of assistance, if you know if it comes up (Wade).

Not only does Wade feel comfortable addressing the topic with clients due to his own beliefs, he also saw a disparity between himself and colleagues who did not have personal beliefs and were uncomfortable bringing it up in case the conversation went to a place where they felt they could not assist. Similarly, those who were raised in a religious context felt comfortable:

> Well, so I was brought up in a very family with a very strong faith. And so it's a very natural topic to me, I have people in my, in my social circle, that or my family circle that for whom faith is really the groundwork that everything else is based on. So I feel, you know, very comfortable exploring that with, with patients. I guess I'm lucky in that sense (Barbara).

Alternatively, Susan, who was most vocal about her atheism (from birth) also felt that her atheism was something that made her more comfortable:

> Yeah. And I think that, like, because I was like, born and raised atheist, it makes me more comfortable kind of exploring those things. But I feel like if I was atheist, but you know, converted atheist, I might have some, I guess, background, you know, feelings about religion that might make me not as open to asking questions or a little bit more judgmental about, you know, people's own spiritual beliefs, because I had personally chosen to like, go a different route. So, so yeah, just being a-religious my entire life makes it just all that more interesting, I suppose (Susan).

Elaine made the point that her own spirituality increased her comfort level because it gave her the proper vocabulary to be able to speak with a client with their own beliefs. Having the proper vocabulary is important as it helps the practitioner more effectively echo the language of the client in the psychosocial paradigm, helping the client to feel heard:

> So as a person with their own spiritual practice, and a fairly broad interest in spiritual practices like across the world? I don't think it affects my views. Actually, no, that's not true. I think, I think it actually makes me maybe, well, this is not harmful if I can change my opinion, mid-sentence. I think as a person with a spiritual practice and a general interest in it, it increases my awareness of both the positive and potential negative effects of organized spiritual practice. So it's not like a blanket. I have an entirely positive view or an entirely negative view. But I think the main benefit is just that I'm just comfortable. talking about it, I feel like I'd have a little bit of a leg up because I speak some of the language of spiritual practice and whether it's my own or others, because I'm interested in others as well. It just helps to talk about it in a way that's not so alien or so foreign (Elaine).

While the majority of respondents felt comfortable no matter their own R/S, some felt discomfort due to lack of knowledge:

> Yes, I would say probably most of the times if it comes up I would lean towards saying like I'm not super comfortable. I think a lot of that comes from especially when a person is talking about their specific religion is that I'm not super informed about a lot of religions so I don't actually really kind of know a lot of the belief systems that certain religions hold so I guess sometimes it makes me uncomfortable asking a person to

> explain their beliefs and explain their religion but maybe it necessarily shouldn't make me uncomfortable but I would say my lack an experience with religion makes me slightly uncomfortable because I don't quite understand the support or the role of places for people (Andrea).

Shelley said that she could figure it out if it was brought up but it might make her uncomfortable:

> I think it can be a hard thing as well like someone who comes in who is extremely religious and that's kind of the center focus for them. Sometimes that can be a challenge for me sometimes…people have strong faith [and] I think can figure out how to put it aside right? and deal with the person in front [of me] but I feel like by not having that it's just one less thing I really think about or worry about so… (Shelley).

It is also important to note that all respondents who spoke about some sort of religious affiliation or religious upbringing were speaking from a Christian perspective, though one was raised in the Christian Science tradition and there is some discussion on how closely tethered Christian Science is to mainstream Christianity (Poloma, 1991). This is important because they will not always be dealing only with clients who adhere to a Christian belief system. In fact there is a dearth of non-white, non-Christian, non-women genetic counselors in the profession in Canada. However, I did not ask participants about their ethnic or racial identity and cannot speak on the statistics in this case. Another note is that those who identified as religious more often used the language of faithful or faith-filled rather than religious.

In their study, “The Role and Impact of Personal Faith and Religion Among Genetic Service Providers” Geller et al. (2009) interviewed and surveyed genetic service providers, including genetic counselors. They found that genetic counselors were the most likely out of all genetic service providers to experience “personal value conflicts.” Some genetic counselors felt conflicted or distressed by the possibility of having to disclose their personal beliefs to colleagues or address beliefs with clients in case they were different to their own (Geller et al., 2009). Alternatively, if a genetic counselor is “non-religious” (as it is termed in the article) they reported sometimes feeling judgmental of clients who rely on God or R/S to cope (Geller et al., 2009, p.36). Additionally, some genetic counselors who identified themselves as holding personal beliefs felt that it helped them to deal with work and work-related stress. Another aspect of this connection between personal R/S and work is the relationship of personal faith with scientific information: some professionals did have difficulty reconciling these two things particularly in the prenatal setting, further indicating that these issues arise more prominently during prenatal counseling. However, others who identified as having personal faith felt they could override difficulties between their personal faith and genetic science in order to respect scientific progress. Geller et al.'s (2009) study clarifies that their definition of religion may have been too narrow and recognizes that there is growing literature in the area of a broader sense of spirituality within healthcare. I purposefully did not define religion or spirituality before interviewing my participants and also used both terms so that respondents could answer in a way that best suited them with room for them to interpret the terms.

In "Genetic Counselors' Religiosity & Spirituality: Are Genetic Counselors Different from the General Population?" (2009) Cragun et al. conclude that in the US context, genetic counselors are "significantly more likely to report having no religious affiliation, significantly less likely to believe in an afterlife, and significantly more likely to be agnostic and atheist when compared to the U.S." (2009, p.553). The major difference between the rates of religiosity or spirituality in my study and this study could be due to different understanding of religiosity or spirituality wherein they used specific measures in a survey-based study and I let participants self-define or due to the difference between genetic counselors in the US and Canada.

5.1 Recognition of R/S Bias

In the educational and ethical genetic counseling literature, R/S is often mentioned regarding the recognition of bias for genetic counselors. It is deemed very important for one's bias to be acknowledged so a genetic counselor can properly provide care and communicate effectively with the client. In the psychosocial paradigm of counseling, this is framed as acknowledging and putting one's own beliefs and biases in "brackets" to avoid presumptions, so one can listen and learn more effectively from the experience of the counselee (Djurdonovic, 2009). Similarly John Weil points out in his book *Psychosocial Genetic Counseling (2000)* that "examination of one's own ethnocultural identity, culture, and history is essential to recognizing the values, assumptions, limitations, stereotypes, and biases that are the inevitable underpinnings of one's own worldview" (Weil, 2000, p.237). While he makes this point in the context of ethnocultural awareness, he mentions R/S in genetic counseling as a part of the "ethnocultural imperative". Given that most respondents were most familiar with the Christian context in general as well as in their own personal beliefs and values, they all stated to some extent that they were aware of their beliefs or biases in relation to R/S, this took shape both for those who identified as spiritual or religious and those who did not. For instance, Rebecca states

> I am an atheist. So I'm aware of that. And I am aware of how that could affect my counseling and my ability to hear and understand other people's perspectives. And so I hope that having that awareness will make sure that I, you know, I, that I'm open, right, like, that's my perspective, but I'm very open to other people's perspectives and what you know, I know they are entitled to their own perspective, and I know that it will inform their viewpoints and decisions. So I hope that my awareness of where I stand, and my… I know I need to focus on making sure I hear them and ask open ended questions, and understand how their perspectives play into their decision making and information and everything. Sure, yeah. Okay. I'm open to that, for that my perspectives are not influencing even how I'm giving information or how I'm leading the discussion, or what questions I'm asking them or passing judgment back (Rebecca).

Alternatively, from a faith perspective, Wade was raised in an organized Christian tradition and feels that his faith and his awareness of it is helpful to his practice:

> I mean, part of, I mean, well, I think you have to start on an individual level first. Because I think having a good grounding and your own kind of faith issues and belief issues, I feel is quite important at times, because you know, where you're at, and what your biases are, as well. And, and knowing your biases are very important in dealing with other people, first of all. Secondly, I mean, it just gives you a bit more grounding in terms of your own resilience to kind of, you know, things as they arise. And, and, you know, I think, your own personal faith issues kind of sometimes help through difficult times (Wade).

As someone who was raised in a faith but now feels conflicted about it, Holly sees the complicated nature of addressing R/S with clients while also acknowledging your own position:

> You're connecting with someone on a personal level, about something pretty meaningful and serious in their life. So I don't think it's necessary to shut down every part of your personal self. But some of those things like I do have to kind of like, mute, and be respectful of like people's takes. And yeah, so I think sometimes maybe at least, like, to me being hesitant to bring certain topics up or to, like, get into nitty gritties. Because I can't, in my own, like, personal, good faith be like, Oh, yes, you have this take that I like,

> in my own personal life I disagree with and I can't like follow with them and explore that more. So it saddens me a little bit like, personal limitations of mine that like sometimes that interferes with those conversations. But it's also me, you know, like not wanting to get into it. And it's not about me, it's about them. So it's complicated. It doesn't come up often, like I'm saying, and like, these are kind of rare cases. But sometimes like that conversation is stifled a little bit by some of the medical setting and trying to be impartial and trying to like, give them their space (Holly).

As Holly points out there is also a concern that in bringing in R/S to the conversation you are not allowing the client their own space to communicate what they were planning to express. She points out that she wants to enter into an interpersonal space with the client but also give them their own space. This concern is echoed in Fanning's (2016) chapter on spiritual assessment in genetic counseling, in that the benefits of bringing up R/S before a client does might be outweighed by the negatives. The genetic counseling practice-based competencies also stress maintaining "professional boundaries by ensuring directive statements, self-disclosure, and self-involving responses are in the best interest of the client" (Doyle et al, 2016, p.877).

Respondents also discussed the ways in which they make clients comfortable to discuss anything that comes to mind, especially R/S which may be perceived as not medically pertinent by the clients (White, 2009; Bartenbaker Thompson et al., 2016). Recognition of bias also includes whether the genetic counselor even thinks to bring up R/S depending on their own context:

> But then I, since I'm not a practicing religious person, maybe I'm less likely to bring that up to a patient because it's not something that I think about in my in… for myself, so I wouldn't think about it with a patient, I wouldn't think that they are thinking of that kind of thing (Katey).

5.2 Perceived Client Comfort Discussing R/S

In this study, most responses to do with patient comfort regarding R/S focused on making clients feel comfortable so they could bring up anything, including R/S, and to help them feel comfortable once they had brought up the topic:

> Yeah definitely just being there and showing them I'm open to discussing that and hearing their belief.…So I would say definitely being able to address all of the patient's

> concerns and everything that the patient needs not just the immediate you know, planning medical information, giving them all the kind of scientific stuff, but being able to make sure the patient has the ability to voice their feelings and being able to explore those feelings and kind of a safe environment and being able to address not just the scientific and the medical information, but also the other aspects of a genetic diagnosis or a genetic issue (Katey).

Similar to Katey, and in line with the literature on avoiding bias, Susan said she tried to make clients comfortable to discuss R/S by:

> I guess not to make assumptions and to ask those open-ended questions. And then, yeah, that's, that's basically it, to kind of come into every single appointment with a fresh, you know, fresh perspective on ‘Okay, who is this person?’ And, and, you know, using that to ask my open-ended questions, instead of making those assumptions (Susan).

Even if a practitioner has success in eliciting R/S information from a client who feels it is important, what happens if those values or beliefs are at direct odds with the information that the genetic counselor is trying to communicate? As Mary White says: “if counselors suspect that faith claims may lead to refusals of care or decisions that are at odds either with the client’s medical interests or the counselor’s own religious values, they may wish to avoid them” (2009, 73). This fear was reflected by some of the respondents of this study:

> But that's maybe sometimes where we get it can lead to discomfort, I guess, when it's like, like I was saying earlier with when it sometimes goes against like the actual genetic information, like the information that I'm there to talk about, like, sometimes that leads to discomfort as well (Holly).

Rebecca also expressed that there was some discomfort for her surrounding the “hard science” aspects of her genetic counseling practice because of her own spiritual beliefs, but that also her own difficulties integrating these beliefs into her work give her more empathy towards clients:

> And I think especially as I've gotten older, sort of, I've revisited my ideas and practices around spirituality and it's been kind of difficult integrating those spiritual beliefs or those spiritual ideas with the hard science and the, you know, the hard evidence that I deal with day in and day out, and it does make me reflect on the fact of like, how, how do patients integrate all of this very concrete seeming data, or these kind of confusing scientific

> concepts with, you know, the, the perhaps more intuitive beliefs that they have, or just the beliefs that they've been raised with for their whole life and our and are now sort of having to grapple with the discrepancy between what they're being told in a healthcare setting versus what they what they believe (Rebecca).

In existing literature there are two aspects to client comfort in relation to the topic of R/S in the genetic counseling context: one, the way in which genetic counselors are careful to make clients comfortable to talk about anything including R/S (without prompting) and two, genetic counselors perceptions of clients comfort of addressing the topic at all. While most genetic counselors seem to be comfortable to discuss R/S if a client brings it up, some feel that going too deeply into it might lead to uncomfortable conversations that bring up points that contradict the scientific information that the genetic counselor is trying to communicate (Reis et al. 2007). As has been discussed before, Fanning feels that the use of spiritual assessments in genetic counseling that promote the genetic counselor asking the client about R/S without the client bringing it up first has harms that perhaps outweigh the benefits. The point of view of the client about R/S in genetic counseling is then expressed in "Be prepared if I bring it up." (Bartenbaker Thompson et al., 2016) Bartenbaker Thompson et al. concluded that "responses suggest routine or comprehensive R/S assessments or discussions are not necessary and that genetic counselors would be best equipped to help all their patients if they were prepared to listen, be supportive, and make referrals when R/S issues arise in clinic." (Bartenbaker Thompson et al., 2016, p.945) The referral aspect arises because the respondents were of the opinion that genetic counseling was about science and therefore genetic counselors are not qualified to address R/S and there are other resources available for addressing R/S (Bartenbaker Thompson et al., 2016). Alternatively, John Weil, in *Psychosocial Genetic Counseling* advocates that genetic counselors should in fact raise R/S with clients "since the counselee may not consider these topics to be relevant, appropriate, or of interest to the counselor" but they may in fact be important (Weil, 2000).

The data of Bartenbaker Thompson et al. (2016) points to clients feeling that it is not the place of the genetic counselor to bring up R/S concerns. However, it did show that clients feel that the genetic counselor should be able to engage in conversation about R/S should the client bring it up as well the counselor should know what R/S resources and referrals to access should the need arise. My interviews also reflected that genetic counselors felt more comfortable addressing R/S if the client brought it up because it denoted a desire to bring it into the counseling session. Overall, participants were not uniformly comfortable addressing R/S with their clients whether the client brought it up or not. This was due to personal R/S affiliations or on-affiliation causing discomfort in regard to particular topics such as: R/S affiliations different to their own or R/S they felt unfamiliar with, as well as a perception of lack of comfort on the part of clients. As well participants were aware of their biases in considering addressing R/S whether they had an R/S affiliation or not.

Bartenbaker Thompson et al's study also reported a minority that felt R/S conversation should be identified as an option in the genetic counseling process because it shows the counselor to be someone who is taking into account the whole person rather than just disease (Bartenbaker Thompson et al., 2016, p.947). The consideration of whether genetic counselors are comfortable addressing R/S with clients leads us into our next section: are genetic counselors in fact prepared if a client brings R/S up? And does the medical system allow them to feel supported in the face of these discussions?

Chapter 6: Resource Availability/ Management in Regard to Religion and Spirituality in Genetic Counseling

What is needed for genetic counselors to feel more comfortable addressing R/S when it is pertinent or requested? In short, more readily available resources, such as continuing education on R/S in genetic counseling in both text and conference or seminar form, more knowledge of spiritual or pastoral care in the institutional structure, and finally, as is the case in much of the medical world: more time with clients.

6.1 Resources and Support

When asked if they felt they had enough support to address R/S and if not what would they like, the majority of participants cited wanting more continuing education opportunities on R/S in genetic counseling as well as more set guidelines for whom to reach out to in the case of an R/S issue that they felt out of their depths, as well as more time as mentioned previously. Study participants, acknowledged R/S as a resource for clients and patients that genetic counselors can help clients access and also discussed the management of R/S resources on the part of institutions in which they work. The genetic counselors interviewed in this study clearly echo this point in their discussion surrounding lack of general institutional resources as a barrier to their having considered addressing R/S in their practice:

> That's a good question. I think I would have to look into it more to know if we have those supports here. Okay. My gut says no, we probably don't have a lot, we have something but it's probably not a lot and probably there are better, I probably would look at what our institution has. And then I probably would go elsewhere to find patients the support that they need, I probably would reach out to community services and see what else there is (Katey).

However, many respondents cited not knowing about what institutional resources there were in their particular institutions due to not feeling they had ever entered into a deep enough R/S discussion with a client:

> I mean, I think that I could probably reach out to, to, you know, management or to, to the social workers who were associated with and ask, Hey, do you know of where these resources are in the hospital and then just kind of like, keep it in my back pocket so that if

> it does come up, I can just bring it right to the patient. So far, it hasn't been a problem (Susan).

The question then becomes whether these discussions have not been entered into in depth because there is not broad institutional knowledge sharing regarding addressing R/S in genetic counseling.

In a particular instance, in regard to acknowledging R/S as a client resource, Wade was talking to a client who had multiple children with the same condition who wanted some help with childcare and he asked whether she had thought to ask her church community because he knew she was an active participant in the Catholic church. Wade acknowledged his clients R/S community as a resource to access to support her and also had to make these connections to external R/S resources in the relatively short time span of one or two genetic counseling sessions:

> Sometimes as an outside observer. Once you have an understanding of where the family is coming from, you can kind of say, Okay, well, have you tried this? Oh, no, she hadn't. Then she said, Oh, that's a good idea that I might actually pursue, because she was thinking, Well, is there government funding for this? And you know, there really isn't, you know, it's, it's limited, right? So, it's trying to kind of, again, work with what you got. That's just, you know, another, just little things like that. I mean, it's not that, okay, it's this big, huge, you know, spiritual discussion or anything that goes on. But, you know, are there ways of support that can happen with existing resources that we're dealing with (Wade).

Wade was the most clearly religious of the study participants, having spent time in seminary and being raised in an organized Christian tradition. He was the most comfortable discussing spirituality, both with me and with his clients. Given his background, he was also aware of other resources to get this mother the support she needed; getting volunteers from her church proved successful. Recognition of R/S is helpful in more than just heuristic and decision-making contexts, but also provide social and other supports to many clients.

Lack of time was listed as a barrier in all of the literature on spiritual assessment in genetic counseling as well, however it most often referenced structured spiritual assessment rather than spiritual assessment on an individual basis (Reis et al. 2007; Weil, 2003; Bartenbaker Thompson et al, 2016; Fanning, 2016). Lack of time is due in part to the lack of genetic counselors in Canada: there are only about 270 active genetic counselors (as of 2019 in Abacan et al.). In addition, they are often only found in larger metropolitan areas with people from rural communities travelling long distances to see them. There is also often a waiting list for genetic counseling appointments given the limited number of genetic counselors (Martin et al, 2018). Number of genetic counselors, geographical locations of genetic counseling practices, and waiting list length vary depending on the province, because Canada's healthcare system is not a federal system, but "rather a collection of provincial and territorial health insurance plans subject to national standards" (Martin et al. 2018, p 1718). The interviewees for this study represent only four provinces, each of which provides its own unique context for their perceptions of their practices and the local institutional and organizational structures. When asked whether she felt she had enough support to address R/S with her clients Andrea said:

> Oh yeah, I think probably don't have enough support. My first thought when you ask that question was I don't have enough time to talk about religion so I think you know ideally if our sessions were like three hours long and you could expect and like you know, talk about all those things and really explore that would be one thing (Andrea).

Shelley makes the point that given the time sensitivity of prenatal genetic counseling as well as the perceived importance of R/S in that context, she feels she would like more guidance and support in regard to R/S were she to be working in that context:

> Oh, you know, and I think if I stayed in prenatal I would probably be seeking out a little bit more, maybe guidance and support in that area, just because the topics are so touchy and time sensitive and so important for the family to make the best decision they can in the moment right and, and if they're going to be using their faith, to guide that, I feel like probably I would need to maybe understand those, how that influences decisions (Shelley).

Wade also makes the point that genetic counseling also often happens in acute medical circumstances which affects the timeline of the counseling session and also its content*:*

> Yeah, because we have limited time. You know, it's, we're there in acute circumstances, like, you know, there's lots of stuff going on at that time, you know, lots of emotions, you know, sometimes denial, you know, all of those things come up at the points, you know, and depending, you know, where they're at, in their decision making, and so forth. It's, it's, it's, you're, you're helping them to move through that period. as best they can. I mean,

> you're not there, as a genetic counselor to take on a long-term counseling assignment with that, that family, they have to go elsewhere for that (Wade).

However in this case, the acute timeline also could be an argument for addressing R/S as it is also a time with many intense emotions and coping strategies are also very important. But, given the limited nature of genetic counseling, as Wade says, they are not there to take on long term counseling projects. In the case of R/S this may mean that knowledge and ability to refer elsewhere such as spiritual care is an asset for genetic counseling practice.

6.2 Spiritual or Pastoral care as Institutional Resource

Six of the 13 respondents of this study did not have a clear idea of how to get in touch with spiritual or pastoral care in their respective contexts:

> To be honest, I don't think I really have any relationship with them, I'm aware that they exist. But we pretty rarely, I can't think of a time when we, you know, for example, referred a patient to pastoral care, spiritual care for additional you know service or care. And most of our patients are seen on an outpatient basis as well. And so they have pretty limited interaction with other services or institutions within the hospital system. And so really, we don't, I'm not aware of any relationship that either I specifically will nor my particular clinic have with the pastoral care within the hospital (Rebecca).

Those who did have a good sense of how to access the spiritual care in their institution worked in a particular context such as neuro-genetics that placed them in a more integrated space within the hospital system. Of course, offering the referral does not mean that the client will take it. However many clients are not aware it is even an option:

> You know, if I see elements that need to be addressed, that's a little bigger than me, then we'll make referrals outside. But I never actually made a referral to psychology, spirituality, except for one in ALS. But I knew she had already seen the spiritual counselor and I thought, you know, to be a great conversation to go back. But you know, when I'm in the ALS clinic, I talk about all the services and I always bring her up (Gloria).

Wade reported a close relationship with pastoral care over the course of his career which could be due to his own deep faith as well as the fact that out of all the participants he had been practicing the longest. Elaine was also very aware of spiritual care at her institution:

> We're really lucky, we have at the hospital where I work, we have a spiritual care, an entire spiritual care department. And they do have various leaders or spiritual care providers that they can reach out to depending on the particular faith and spiritual leanings of a patient. So we have we have really nice access (Elaine).

6.3 Religious/Spiritual Education

The study participants were also asked about their educational experience surrounding R/S. Answers varied greatly between respondents, and in no clear way connected to age (years since they were trained) or to particular programs. This makes sense given that it has been established that there is no clear consensus on the role of religion or spirituality in genetic counseling, nor on spiritual assessment in genetic counseling. However, the *2013 Review and Update of the Genetic Counseling Practice Based Competencies by a Task Force of the Accreditation Council for Genetic Counseling* shows that the updated practice-based competencies directly reference religious and cultural beliefs under the 3rd domain: Education. It states that in order to effectively educate clients about the necessary genetic information the practitioner must "identify factors that affect the learning process such as intellectual ability, emotional state, socioeconomic factors, physical abilities, *religious and cultural beliefs,* motivation, language and educational background." (Doyle et al, 2016, p. 877, my own emphasis) Further in the second domain: Interpersonal, Psychosocial, and Counseling Skills, the phrase "cultural beliefs" is referenced in regard to applying genetic counseling skills in a "culturally responsive and respectful manner" (Doyle et al, 2016, p. 877). The responses from the participants support that these PBCs are generally followed in current genetic counseling masters programs in that they referenced that R/S was most often directly referenced in regard to cultural competency:

> I think our training lumped in culturalism and religion all in one. I think they did a decent job of giving us the basics I do think they it's something that's very, it's raised from like day one of our training that this is critically important to connect with these families on their level. But I would say it's possibly a little bit more culturalism than religion in what I got (Shelley).

However the same respondent pointed out that they are “really grateful that I took classes in CEGEP and university learning about the big religions and I'm actually really grateful to have that knowledge kind of in my in my arsenal” (Shelley). Elaine stated that their program did not address the specifics but did make them aware that R/S could have potential impact on patients, “But in terms of the details of, you know how to address it or what to be aware of that, that wasn't included” (Elaine). There were respondents who felt that their programs prepared them to address R/S with patients. Beth felt prepared given their education focused on listening:

> I would say yes. Because part of my training, a lot of it has to do with being able to reflect and acknowledge what the patients are saying right? That can cover a wide variety of topics (Beth).

For her, R/S is but one of many topics that can addressed in a client-centered approach that is taught in most genetic counseling programs. Only one respondent reported that R/S was addressed directly and specifically in her training outside of discussions of termination in the prenatal context:

> I mean, I feel like it was addressed pretty thoroughly in my training and my particular training program in in that we did explore, you know, articles or readings of patients from very particular faith backgrounds, or, for example, indigenous communities with their particular spiritual traditions (Rebecca).

Another aspect to consider in genetic counseling education is the required practicum and the context in which that is done. For example, one of the respondents did their training in Cincinnati, Ohio with a significant Christian population that affected the R/S exposure she had during her practicum and during her degree:

> I actually do … we had a couple I want to say assignments or like sessions about religion and genetic counseling. And I remember reading a really great article about spirituality and genetic counseling and, providing religious services for genetic counseling. And I, and again, I think it came up a lot more where I was previously situated. And we were at like a pretty big center. So it was we had a lot of services there. So I do think I was trained pretty well on that and I'm not sure how other programs do it but and again, it wasn't a ton it was but it was like hey, this is why it could be beneficial to the patient that patients this is how you could approach it (Katey).

Raphaelle felt that her practicum was helpful in introducing her to new situations and aspects of the profession but that there is still much room for improvement and growth for R/S education:

> But and I guess like in my practicums, too, then you experience people, like all different people. And we had a chance to kind of speak with our supervisors at those points about how people make decisions. But I would say that it's like there's room for improvement there. I do think that there could be more (Raphaelle).

Overall many participants felt that their existing knowledge of R/S came from within education on multiculturalism, practicum experience, or through education outside of their genetic counseling program. The most requested resource to be added was continuing education. Even Katey, who felt her training was good and comprehensive, believed more education would be beneficial to her practice:

> No, I would just say I do definitely think I could learn more and I would if there was like a seminar or something I could take to improve my knowledge and how to support patients and how to like how to bring I'm not afraid to bring up spirituality and religion, but I don't and I think if there was a seminar on how to do that, and if it would be beneficial, I would definitely take that and I would incorporate it into my practice. Yeah, so I said that I thought my training was good. And I do think it was, but I do think there that I could learn a lot more (Katey).

In regard to accessing resources for their clients in terms of R/S support systems and information, most respondents felt that it was something they would have to find for their clients outside of their work institution, such as suggesting the church community for childcare above. Susan stated that if a client asked for tradition specific spiritual resources:

> I guess I feel like if they were to request the resources, I would be able to figure out where they were most likely, but I would have to, you know, kind of say, you know, give me your contact information. I'll let you know when I have this information (Susan).

However, it was the experience of most respondents that if outside R/S opinions were needed that the client would suggest it themselves or state that they needed to consult a religious authority figure before making a decision. In relation to this, in regard to continuing education, many respondents citing wanting to know where to access or talk to religious leaders or where to send clients:

> That's a good question. I think I would have to look into it more to know if we have those supports here. Okay. My gut says no, we probably don't have a lot, we have something but it's probably not a lot and probably there are better, I probably would look at what our institution has. And then I probably would go elsewhere to find patients the support that they need, I probably would reach out to community services and see what else there is. . . I probably would do a lot of my own research and my own digging. So I'm thinking if I, I'm picturing running into the situation where I offered to connect to patients or religious supports, and then I found that our hospital did not have really what I was looking for, I would probably first email my whole team and see if anyone knows of anything in the community. And then if not, I would probably just start googling and start calling. And just be like calling different centers and saying like, hey, do you know and if any services or anything like this, we also have a pretty wide patient area. So I do that often. Because some a lot, some of my patients are like six hours away from our physical city. So I do that a lot with other stuff, I would probably do the same. If it came up, yeah (Katey).

Notably despite it being the focus of much research on genetic counseling and R/S, none of the respondents had any knowledge or plans to use a set spiritual assessment despite it being a part of some of the educational materials found. Murray et al. (2020) found that five out of 12 genetic counseling programs teach students to conduct a spiritual survey, and two programs reference teaching the spiritual surveys listed in the Genetic Counseling Cultural Competence Toolkit (2020). The respondents in this study were asked specifically about the HOPE survey as it is the most common but they had not heard of it and the questions also used the language of set spiritual assessment. Sagaser et al. (2016) recommends the development of an assessment specifically in the prenatal context. Reis et al. (2007) conclude by recommending the development of a spiritual assessment tool specifically for genetic counseling. The PBC's however, do not mention spiritual assessment directly at all, indicating that the field of genetic counseling does not prioritize spiritual assessment (Doyle et al, 2016).

Because of the varying nature of the scenarios in genetic counseling practice, most respondents did not feel that they would necessarily bring up R/S with patients due to context and time constraints. However, they all expressed interest in learning more about how to engage in R/S discussion with clients and use that knowledge to provide better support to clients in their practice. Overall, while many respondents were aware of pastoral or spiritual care being available in their respective institutions and all respondents had received some sort of education on R/S in their genetic counseling program, many expressed the desire for there to be more continuing education made available to them on the topic as well as to have a more concrete idea of what resources are available in their institutions and in the surrounding religious communities should the need arise.

Chapter 7: Conclusion

Throughout this thesis, I argued that genetics as a medical field requires special consideration due to its key elements of uncertainty, discussions of experience of illness, and relational and psychosocial elements. Due to these particular markers, genetic medicine perhaps warrants more or equal concern with regard to religion or spirituality than other medical fields. Similarly, genetic counseling holds a unique space both in genetic medicine and medicine overall given the combination of scientific and the psychosocial knowledge and skills as well as genetic counseling's relative autonomy within medicine. As well, the psychosocial knowledge inherent in genetic counseling lends itself to the listening that is necessary to be prepared to listen, hear, and reflect clients R/S concerns. However, given the short 40-year time period that genetic counseling has been an official profession and the overall devaluation of R/S in medicine (McGuire, 2008), not a lot has been done to research the relationship between genetic counseling and R/S or to develop concrete tools or resources for genetic counselors to address R/S in their practices. Also, as this study demonstrates, genetic counselors are either addressing R/S with clients with little support or evidence of its effects or not addressing R/S at all out of lack of training or fear (White, 2009; Reis et al. 2009; Cragun et al, 2009). Many respondents in this thesis expressed that they were interested in joining the study because they had not previously given it much thought and wanted to do so in the future or felt it was a topic that had not been given enough attention in their training and daily work life.

While addressing R/S is not the main goal of genetic counseling, it arises and respondents were not altogether comfortable or sure of how to address the topic with their clients. However comfort increased when the client brought up the topic without prompting or if the genetic counselor was comfortable with their own R/S affiliation and how it interacted with their practice. The participants of this study varied in their personal R/S affiliations but more identified as religious or spiritual than not. Respondents also lacked consistent tools or support from their education or place of work to know exactly how to engage in R/S discussions with clients though many did know where to access resources. Overall lack of time was the greatest resource barrier to addressing R/S with genetic counseling clients.

7.1 Future recommendation: Tools and Research

Given the limitations of this study, especially the small sample size, it is not appropriate for me to make broad generalizable claims as hoped for and stated in the consent form (Appendix B). However, given my collected responses and review of literature, I will make some recommendations for the future of R/S within genetic counseling. While Reis et al. (2007) argue for the development of a spiritual assessment tailored to genetic counseling, I think the psychosocial and client-centered aspects of genetic counseling make it well-suited for case-by-case evaluation. That does not mean however, that there does not need to be further education or resources on the matter. In order for R/S to be addressed on a case-by-case basis, this study has shown that there could certainly be more concrete education to guide counselors on how to have those conversations and when they may be most helpful. As well, it would be helpful to codify resources and protocols for when R/S conversations may reach beyond the purview of the genetic counseling session.

The future of R/S in genetic counseling education could more explicitly address R/S training with more direct attention to R/S as a possible coping framework and heuristic mechanism (White, 2009; McGuire, 2008; Baty, 2009) for clients rather than just one of many aspects of genetic decision making in regard to termination of pregnancy or as an aspect of multi-cultural awareness in a client centered practice. While genetic counselors are given tools that can be used for R/S discussions such as active listening and mirroring of language (Weil, 2000; Djurdonovic, 2009). But these tools may not fully incorporate the level of engagement that clients are looking for when discussing religious or spiritual concerns. This is especially true given the broadening of the definition of spirituality seen throughout this thesis, especially in conversation outside of the prenatal context.

Future studies about the perception of clients regarding their views on spirituality and meaning making in their experience of genetic counseling would be helpful for developing new tools and educational curriculum. The one existing study “Be Prepared if I Bring It Up: Patients’ Perceptions of the Utility of Religious and Spiritual Discussion During Genetic Counseling” only asked questions regarding the routine introduction of R/S into the genetic counseling practice (Bartenbaker Thompson et al, 2016). Therefore a study that probes further about which factors clients used to make decisions in the genetic counseling context would be informative in determining what new tools and educational curricula need to be developed. These tools could provide a broader sense of R/S that allows genetic counselors to learn how to better shape R/S conversations with clients when they come up. Through these new tools and additional curriculum, genetic counselors can be less fearful and be better prepared to have fruitful conversations when R/S does comes up.

While overall, the respondents in this study communicated that they had has some education on the matter or that they felt mostly comfortable addressing the matter with patients, there was lack of consistent preparedness, which was also reflected in the aforementioned genetic counseling graduate school curriculum study (Murray et al. 2020) as well as Reis et al. (2007), where responses varied greatly. New direct curricula on how to enact a case by case spiritual assessment could lead to more consistent and fruitful genetic counseling session where R/S is involved. Given genetic counseling's varied place within different medical systems and respondents overall reticence or lack of knowledge, and lack of experience regarding spiritual care where they worked, further education and resources on when and how to refer to spiritual care could be very helpful in the future.

Works Cited

Abacan, M., Alsubaie, L., Barlow-Stewart, K., Caanen, B., Cordier, C., Courtney, E., Davoine, E., Edwards, J., Elackatt, N. J., Gardiner, K., Guan, Y., Huang, L.-H., Malmgren, C. I., Kejriwal, S., Kim, H. J., Lambert, D., Lantigua-Cruz, P. A., Lee, J. M. H., Lodahl, M., … Wicklund, C. (2019). The Global State of the Genetic Counseling Profession. *European Journal of Human Genetics*, *27*(2), 183–197. https://doi.org/10.1038/s41431-018-0252-x

Anderson, R. R. (2009). Religious Traditions and Prenatal Genetic Counseling. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, *151C*(1), 52–61. https://doi.org/10.1002/ajmg.c.30203

Baty, B.J. (2009). Risk Communication and Decision-Making*:* in *A Guide to Genetic Counseling* eds. Schuette, J. L., Yashar, B. M., Uhlmann, W. R., Uhlmann, W. R., Schuette, J. L., & Yashar, B. pp. 207-250 (2009). John Wiley & Sons, Incorporated.

Bartenbaker Thompson, A., Cragun, D., Sumerau, J. E., Cragun, R. T., De Gifis, V., & Trepanier, A. (2016). "Be Prepared if I Bring It Up:" Patients' Perceptions of the Utility of Religious and Spiritual Discussion During Genetic Counseling. *Journal of Genetic Counseling*, *25*(5), 945–956. https://doi.org/10.1007/s10897-015-9922-9

Biesecker, B. (2001). Goals of Genetic Counseling. *Clinical Genetics*, *60*(5), 323–330. https://doi.org/10.1034/j.1399-0004.2001.600501.x

Bryant, Antony & Charmaz, Kathy. (2007). Introduction: grounded theory research: methods and practices. In A. Bryant, & K. Charmaz *The SAGE Handbook of Grounded Theory* (pp. 1-28). SAGE Publications Ltd, https://dx.doi.org/

Canadian Board of Genetic Counselors. (2022). *Canadian Certified Genetic Counsellors Qualified and Competent Genetic Counselling Service Providers*, Canadian certified genetic counsellors - cagc-accg.ca. CBGC CCCG. Retrieved April 1, 2022, from https://www.cagc-accg.ca/doc/CCGC%20Flyer%20FINAL%20-%20English.pdf

Government of Canada (2013, February 5). *Genetic Counselling*. Canada.ca. Retrieved May 3, 2022, from https://ww,w.canada.ca/en/public-health/services/fertility/genetic-counselling.html

Churchill, L. R. (2009). Religion, spirituality, and genetics: Mapping the terrain for research purposes. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, *151C*(1), 6–12. https://doi.org/10.1002/ajmg.c.30195

Clarke, A. J., & Wallgren-Pettersson, C. (2019). Ethics in genetic counselling. *Journal of Community Genetics*, *10*(1), 3–33. https://doi.org/10.1007/s12687-018-0371-7

Cragun, R. T., Woltanski, A. R., Myers, M. F., & Cragun, D. L. (2009). Genetic Counselors' Religiosity & Spirituality: Are Genetic Counselors Different from the General Population? *Journal of Genetic Counseling*, *18*(6), 551–566. https://doi.org/10.1007/s10897-009-9241-0

Doehring, C. (2019). Using spiritual care to alleviate religious, spiritual, and moral struggles arising from acute health crises. *Ethics, Medicine and Public Health*, 9, 68–74. https://doi.org/10.1016/j.jemep.2019.05.003

Doyle, D. L., Awwad, R. I., Austin, J. C., Baty, B. J., Bergner, A. L., Brewster, S. J., Erby, L. A. H., Franklin, C. R., Greb, A. E., Grubs, R. E., Hooker, G. W., Noblin, S. J., Ormond, K. E., Palmer, C. G., Petty, E. M., Singletary, C. N., Thomas, M. J., Toriello, H., Walton, C. S., & Uhlmann, W. R. (2016). 2013 Review and Update of the Genetic Counseling Practice Based Competencies by a Task Force of the Accreditation Council for Genetic Counseling. *Journal of Genetic Counseling*, *25*(5), 868–879. https://doi.org/10.1007/s10897-016-9984-3

Djurdonovic, Luba. Psychosocial Counseling*:* in *A Guide to Genetic Counseling* eds. Schuette, J. L., Yashar, B. M., Uhlmann, W. R., Uhlmann, W. R., Schuette, J. L., & Yashar, B. pp. 133-175 (2009). John Wiley & Sons, Incorporated.

Ehman, J., Ott, B., Short, T., Ciampa, R., & Hansen-Flaschen, J. (1999). Do patients want physicians to inquire about their spiritual or religious beliefs if they become gravely ill? *Arch Intern Med*, *159*, 1803–1806

Fanning, J. B. (2016). Genetic Counseling and Spiritual Assessment. *Normative and Pragmatic Dimensions of Genetic Counseling* ed. J.B. Fanning (Vol. 124, pp. 103–133). Springer International Publishing. https://doi.org/10.1007/978-3-319-44929-6_5

Fanning, J. B., & Clayton, E. W. (2009). Religious and Spiritual Issues in Medical Genetics. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, *151C*(1), 1–5. https://doi.org/10.1002/ajmg.c.30191

Geller, G., Micco, E., Silver, R. J., Kolodner, K., & Bernhardt, B. A. (2009). The Role and Impact of Personal Faith and Religion Among Genetic Service Providers. *American*

Journal of Medical Genetics Part C: Seminars in Medical Genetics, *151C*(1), 31–40. https://doi.org/10.1002/ajmg.c.30193

Hutchinson, T. A. (2017). A New Vision for Healthcare. In T. A. Hutchinson, *Whole Person Care* (pp. 3–10). Springer International Publishing. https://doi.org/10.1007/978-3-319-59005-9_1

Kallio, H., Pietilä, A.-M., Johnson, M., & Kangasniemi, M. (2016). Systematic Methodological Review: Developing a Framework for a Qualitative Semi-Structured Interview Guide. *Journal of Advanced Nursing*, *72*(12), 2954–2965. https://doi.org/10.1111/jan.13031

Koenig, H. G. (2000). Religion, Spirituality, and Medicine: Application to Clinical Practice. *JAMA*, 284(13), 1708–1708. https://doi.org/10.1001/jama.284.13.1708-JMS1004-5-1

Larson, D. B., & Larson, S. S. (2003). Spirituality's Potential Relevance to Physical and Emotional Health: A Brief Review of Quantitative Research. *Journal of Psychology and Theology*, *31*(1), 37–51. https://doi.org/10.1177/009164710303100104

Martin, D., Miller, A. P., Quesnel-Vallée, A., Caron, N. R., Vissandjée, B., & Marchildon, G. P. (2018). Canada's Universal Health-Care System: Achieving its Potential. *The Lancet*, *391*(10131), 1718–1735. https://doi.org/10.1016/S0140-6736(18)30181-8

McAllister, M. (2001). Grounded Theory in Genetic Counseling Research. *Journal of Genetic Counseling*, *10*(3), 233–250. https://doi.org/10.1023/A:1016628408498

Mcguire, Meredith. (2008). *Lived Religion: Faith and Practice in Everyday Life*. https://oxford.universitypressscholarship.com/view/10.1093/acprof:oso/9780195172621.001.0001/acprof-9780195172621

Murray, A., Warren, N. S., Bosanko, K., & Williamson Dean, L. (2020). Genetic Counseling Graduate Training to Address Religion and Spirituality in Clinical Practice: A Qualitative Exploration of Programs in North America. *Journal of Genetic Counseling*, *29*(6), 1245–1258. https://doi.org/10.1002/jgc4.1289

Post, S. G., Puchalski, C. M., & Larson, D. B. (2000). Physicians and Patient Spirituality: Professional Boundaries, Competency, and Ethics. *Annals of Internal Medicine*, *132*(7), 578. https://doi.org/10.7326/0003-4819-132-7-200004040-00010

Puchalski C. M. (2010). Religion, Medicine and Spirituality: what we know, what we don't know and what we do. *Asian Pacific Journal of Cancer Prevention: APJCP*, *11 Suppl 1*, 45–49.

Puchalski, C. M., Vitillo, R., Hull, S. K., & Reller, N. (2014). Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus. *Journal of Palliative Medicine*, *17*(6), 642–656. https://doi.org/10.1089/jpm.2014.9427

Reis, L. M., Baumiller, R., Scrivener, W., Yager, G., & Warren, N. S. (2007). Spiritual Assessment in Genetic Counseling. *Journal of Genetic Counseling*, *16*(1), 41–52. https://doi.org/10.1007/s10897-006-9041-8

Resta, R., Biesecker, B. B., Bennett, R. L., Blum, S., Estabrooks Hahn, S., Strecker, M. N., & Williams, J. L. (2006). A New Definition of Genetic Counseling: National Society of Genetic Counselors' Task Force Report. *Journal of Genetic Counseling*, *15*(2), 77–83. https://doi.org/10.1007/s10897-005-9014-3

Resta, R. G. (2019). What have we been trying to do and have we been any good at it? A history of measuring the success of genetic counseling. *European Journal of Medical Genetics*, *62*(5), 300–307. https://doi.org/10.1016/j.ejmg.2018.11.003

Sagaser, K. G., Shahrukh Hashmi, S., Carter, R. D., Lemons, J., Mendez-Figueroa, H., Nassef, S., Peery, B., & Singletary, C. N. (2016). Spiritual Exploration in the Prenatal Genetic Counseling Session. *Journal of Genetic Counseling*, *25*(5), 923–935. https://doi.org/10.1007/s10897-015-9920-y

Salamone, J. D. (2002). Antidepressants and Placebos: Conceptual Problems and Research Strategies. *Prevention & Treatment,* 5(1), Article 24. https://doi.org/10.1037/1522-3736.5.1.524c

Saldaña, Johnny. Chapter 1: An Introduction to Codes and Coding: in *The Coding Manual for Qualitative Researchers 1st edition,* (2009) pp. 3-21 SAGE Publications Ltd

Siani, M., & Ben-Zvi Assaraf, O. (2017). A Qualitative Look into Israeli Genetic Experts' Insights Regarding Culturally Competent Genetic Counseling and Recommendations for Its Enhancement. *Journal of Genetic Counseling*, *26*(6), 1254–1269. https://doi.org/10.1007/s10897-017-0104-9

Sloan, R. P. (2006). *Blind Faith: The Unholy Alliance of Religion and Medicine*. New York: St. Martin's Press.

Stern, A. M. (2012). *Telling Genes : The Story of Genetic Counseling in America*. Johns Hopkins University Press.

Uhlmann, W. R., Schuette, J. L., & Yashar, B. M. (Eds.). (2009). *A Guide to Genetic Counseling* (Second). John Wiley & Sons. Retrieved July 3, 2022, from https://ebookcentral.proquest.com/lib/mcgill/detail.action?docID=573772

Veach, P. M. C., LeRoy, B. S., & Callanan, N. P. (2018). *Facilitating the Genetic Counseling Process: Practice-Based Skills (Second*). Springer. https://doi.org/10.1007/978-3-319-74799-6

Weil, J. (2000). *Psychosocial Genetic Counseling* (Ser. Oxford monographs on medical genetics, no. 41). Oxford University Press. Retrieved September 28th, 2021, https://ebookcentral.proquest.com/lib/mcgill/reader.action?docID=3053655&ppg=1

Weil, J. (2003). Psychosocial Genetic Counseling in the Post-Nondirective Era: A Point of View. *Journal of Genetic Counseling*, *12*(3), 199–211. https://doi.org/10.1023/A:1023234802124

White, M. T. (2009). Making Sense of Genetic Uncertainty: The Role of Religion and Spirituality. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, *151C*(1), 68–76. https://doi.org/10.1002/ajmg.c.30196

Zuckerman, S. (2021). The Emergence of the "genetic counseling" Profession as a Counteraction to Past Eugenic Concepts and Practices. *Bioethics*, *35*(6), 528–539. https://doi.org/10.1111/bioe.12861

Appendix A: Interview Guide (after pilot interview)

- How old are you?

- Where were did all of your university education take place?
- How did you come to be a genetic counsellor?
- How long have you been practicing?
- Can you describe your job as a genetic counsellor?
- What role if any, does spirituality and/or religion play in your practice as a genetic counselor?
- Do you attempt to determine if spiritual/religious concerns are salient for a client or do you wait for them to bring it up?
- How is acknowledging spirituality or religious concerns important to your patients?
- When a client brings up spiritual/religious belief how do you engage in that conversation?
- When clients bring up spiritual/religious concerns would you say it is more often a doctrinal concern from organized religion or a personal concern?
- Do you use a set spiritual assessment such as the HOPE survey/ are you familiar with it? If yes, could you elaborate on how its use has gone for you. If not, how do you go about addressing spiritual concerns if at all? - get HOPE survey acronym definition
- What does the term whole person/ patient care mean to you if anything?
- If yes, how do you embody that in your practice
- How do you feel that your identification or non- identification with spiritual or religious practice and belief effect your views of addressing these topics with your clients?
- Do you feel your own identification or non-identification with spirituality/ religious associations contribute to your comfort/discomfort in addressing spiritual concerns of patients?
- What is your relationship to pastoral counseling services at the institutions in which you work?
- Do you often use their services?
- Do you feel you have adequate support to address religious and spiritual issues with your patients/clients?

- If you are not, how do you think could get better support to address religious and spiritual concerns?
- Do you feel your education adequately prepared you to address spiritual and religious concerns?
- Do you have anything else you would like to add?

Appendix B: Consent Form

Consent Form for project: “The Recognition of Spirituality in Genetic Counselling: A qualitative study of genetic counselors’ recognition and use of the category of spirituality”

Student	**Student Supervisor**
Emma Paddock, Student	Jennifer Fishman, PhD
Master of Arts	Biomedical Ethics Unit
McGill University	McGill University
emma.paddock@mail.mcgill.ca	jennifer.fishman@mcgill.ca

Purpose of Study

I am a student in the Master of Religious Studies with a specialization in Bioethics McGill University. My research, entitled “The Recognition of Spirituality in Genetic Counselling: A qualitative study of genetic counselors’ recognition and use of the category of spirituality” explores how genetic counselors address the spiritual aspect of the patient, and how recognition of the spiritual practices or beliefs of the patient pertains to treatment of the whole person in regard to genetics. I hope to develop new theory and tools surrounding the recognition of patient spirituality in genetic counseling.

Description of participation

Research participants are asked to complete a interview over Zoom or the phone. If you agree, you will be asked questions concerning your experiences as a genetic counselor, with emphasis on issues regarding spirituality and religion of clients and of yourself. This would not require you to speak of specific clients in any way and would rather address your own practice and reflection on it. With your permission, the interview would be audio recorded. Your participation would require approximately 1 hour of your time.

Risk of harm to participants

The information collected during the interview is likely to be uncontroversial, and thus the research poses only a very small risk of harm to participants. Depending on the information you provide, there is a possibility that during the course of the interview difficult topics that produce mild emotional distress may come up.

Management of Research Information/Data

All records of your participation will be confidential. Only my two supervisors and I will have access to information in which you are identified. With your permission, the interview would be audio recorded and later transcribed. All identifying information will be removed from the transcripts and will be coded with an alphanumeric number. The key linking numbers to participant names will be stored in a separate electronic folder with a password. The audio file and the MS Word document of the transcript will be stored on a password-protected computer. Paper copies of interview transcripts, if they are produced, will be stored in a locked file cabinet in my home and shredded at the end of the project. Audio files will be deleted after transcription. Transcripts will be kept on password-protected computer for 3 years following the interview and then deleted.

Use of Research

The results of this study and de-identified extracts from your interview may be published in my Master's thesis, and may also be used for conference publications, presentations, and published in peer-reviewed journals.

Participation and withdrawal

Your participation is completely voluntary. You may withdraw from the study at any time where practicable, for any reason, and without explanation. If you choose to withdraw from the study, all information you provided during the interview would be withdrawn from the study and destroyed.

Consent and Conditions of Consent

The study has been explained to me and my questions have been answered to my satisfaction. I agree to participate in this study. I will be asked to provide my verbal consent before the interview begins.

Concerns about your Treatment in the Research

If you have any concerns about your treatment as a research participant in this study, please contact the McGill IRB at

McGill University
Faculty of Medicine and Health Sciences
McIntyre Medical Building
#633 - 3655 Promenade Sir William Osler
Montreal, Quebec H3G 1Y6
Tel: (514) 398-3124 Fax: (514) 398-3870