

Development, Experience and Expression of Meaning in Genetic Counselors' Lives:  
An Exploratory Analysis

A DISSERTATION  
SUBMITTED TO THE FACULTY OF THE GRADUATE SCHOOL OF THE  
UNIVERSITY OF MINNESOTA  
BY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY

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August, 2014

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## Acknowledgments

This dissertation project is unquestioningly an amalgam of important influences experienced in both my personal life and professional circles. Of course, I will not be able to thank all of the friends, family members, professors, classmates, students and clients who have helped shape my journey up to this point. Nevertheless, I would like to highlight a few of those who have had direct impacts on my writing of this paper, and to give credit and thanks where they are aptly due.

I want to begin by thanking my participants. Before this project, I knew next to nothing about the field of genetic counseling. Over the course of the project, you have helped me begin to understand the endless importance (and nuances) of balancing the love for knowledge with the drive for helping others in need. And while my role needed to remain that of an interviewer, I truly feel that I have become a better counselor through my time spent with you, waxing philosophical about the meaning of life. Thank you for sharing some of your most private experiences and difficult feelings with me, as well as your laughs and your tears. I am both humbled and grateful.

To my advisor, Pat McCarthy Veach, thank you for all of your support and wisdom over the past six years. I knew just a few minutes into my informational interview with you (long before applying to graduate school), that this was the right field for me. You have also thoroughly convinced me that clinical practice is only as good as its clinical supervision, and I am excited to embrace the role of supervisor for others throughout my career. I must also say that I am always impressed with your innate wisdom, as well as your incredible word-‘smith’ing abilities. And, finally, thank you for

being both patient and committed to my education as a scientist-practitioner. I am definitely better for it.

In addition, I would like to thank the rest of my doctoral committee: Bonnie LeRoy, Matt Hanson, and Carrie Burke. You all graciously accepted an invitation to be involved in this project, with enthusiasm and without pause. Thank you for your insights, direction and support along the way. It's been a long road, but I truly feel it has been less bumpy because of you.

I also want to provide a sincere thank you to my four research assistants on this project. Thank you to Sarah Cronin and Kayte McGuire for assisting me with the transcription process. For anyone who has transcribed one interview, he or she will know that transcribing 68 of them is a monumental effort, which could have been a true deal-breaker. And Dan Cooper and Lindsey Benolken, thank you so much for providing your insights, challenge, humor and dedication to the analysis portion of this project. As 'disagreement' is such an integral part of my chosen method, I could not have asked for two better people with whom to disagree (and agree, of course). Thank you so much for all of your hard work and dedication to this project. It would not have happened without you.

Throughout my graduate school career, my doctoral cohort also provided a special dose of support that is hard to summarize. To Shari, Nicole, Corry, Ziqiu, Sonal, Weiyang and Kangting, you are all amazing people with great passion, direction, and moxie. I wish you all the best and I thank you for providing such a pleasant experience to my professional beginnings.

I want to provide an extra special thanks to my parents, Ralph and Kathy. Your consistent support over the years has absolutely helped me to do my best. I am so thankful that I never once felt pushed, cajoled or judged in any of my academic pursuits. It was always support. And whenever a participant in this study described the importance of family (and this happened a lot), I could not help but imagine the two of you and smile. Also, to my three big sisters, Heather, Theresa and Amy, I am convinced that I am able to bring a sense of empathy and sensitivity to my work with clients from having grown up with such wonderful women in my life. Thank you for being bright lights along my journey and for consistently reminding me of the importance of family.

Ultimately, I cannot begin to quantify (or qualify) the contributions from my amazing life partner and wife, over the past ten years. Courtney, you have a knack for making your challenges sweet and your support a bit salty, but I honestly don't think that I'd want it any other way. In fact, I would not at all be where I am today without your genuine belief in the depths of my potential. I have a long long ways to go, but I want to thank you sincerely for spending your life with me and for being (hands down) the best person I know. You are singular and your integrity shines bright.

And finally, to my firstborn child, Winter. You are such an amazing little bundle of energy; sometimes a ray of light, sometimes a quirky gremlin. Since I was a child, I have deeply wanted to be a father. And now I am yours. You have motivated me long before you were born, and you remain one of the strongest winds in my sails. I don't have much advice for you at this point. But if this project has taught me anything, it has been that while feeling 'better' can be nice, feeling 'deeper' is more meaningful. Always.

## **Dedication**

To Courtney

I am still learning the importance of stepping back,  
from who I want to be (and feel I should be).

And to, instead, just be.

Thank you for showing me why and how.

## Abstract

Genetic counselors routinely engage with patients and families who grapple with questions of *meaning* while making decisions about genetic risk (Biesecker, 2001). Research and theory demonstrate genetic counselors gain important personal insights through their work (Runyon et al., 2010) and grow professionally from self-reflective practice regarding their beliefs and values (Zahm, 2009, 2010). Data are lacking, however, about the nature of the *meaning* genetic counselors bring to the profession and how they directly experience and/or navigate issues of *meaning* within clinical practice over time. Accordingly, a national sample ( $N=298$ ) of practicing genetic counselors completed a survey assessing demographic characteristics and willingness to participate in a semi-structured telephone interview exploring their views on *meaning* as they relate to their clinical work and professional development. Sixty-eight individuals of varied experience levels were interviewed about: 1) how they define a meaningful life for themselves; 2) lifetime sources of influence on their sense of *meaning*; 3) work-related contexts that reaffirm their sense of *meaning*; 4) work-related contexts that challenge their sense of *meaning*; 5) how their sense of *meaning* has changed over time; and 6) reasons for participating in this study. Twenty-five interviews were analyzed using Consensual Qualitative Research methods (Hill, 2012); data saturation was reached at that point. Thirty-six thematic domains and 31 categories were extracted. Common themes included: importance of satisfying relationships; helping others; personal fulfillment; personal and patient experiences of illness and loss; religious and/or spiritual foundations; value conflicts; competing obligations; challenges to *meaning*; development of empathy; resiliency; and increased humility. Results suggest the importance of

professional venues for discussions of *meaning* (e.g., genetic counseling program curricula, continuing education, and peer supervision/consultation). Additional findings, illustrative examples, and practice implications and research recommendations are presented.

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## Chapter 1

### Introduction

*There was this family who had a baby with a very severe metabolic problem. This was a baby who had almost continual seizures, a hyper-movement disorder, and no real awareness of anybody around him... And I became very involved with this family [as their genetic counselor]. This was their first child together and it was a family that was very strong in their faith and very positive. And despite the pretty significant financial and emotional tolls that having their son in their lives presented for them, they were absolutely the best kind of parents!*

*They had decided that they would not take a risk of having another baby, despite the fact that they very much wanted to have another child together. But as the woman was taking the father to have a vasectomy (because both a prenatal diagnosis and abortion were against their faith), she discovered she was pregnant. They decided based on this that they would go against their religious beliefs [to receive genetic testing and potential termination], because they just could not bring another baby into the world with the same condition. They'd seen how much their son was suffering and how limited his quality of life was.*

*So, they pursued testing, but the testing failed. They had driven 700 miles to get to the center where the testing could be performed and there was a problem in shipment. They then had to drive back another 700 miles to have the testing repeated at a time that their son was very ill. The testing was successful the second time... And the day that I called the mother to give her the results that the unborn baby was also affected, her [first] son died in the hospital.*

*The family chose to pursue termination. They really felt they had no other option. But they live in a part of the world where terminations are not easy to acquire. They actually live in a part of the world where people have been killed for performing terminations. So, I made arrangements for them to again drive the 700 miles to terminate this pregnancy. And it was a real crisis of faith for them. Everything that happened to them was a crisis of faith. They felt that their religion had abandoned them, that God had abandoned them, that fairness had abandoned them. They really, really struggled to make it through... And, you know, when situations like that happen, you just wonder how much one family has to take... I don't think there's an answer to that. If there is, I haven't found it.*

-- Anonymous genetic counseling participant

As evident in this actual patient vignette, similar to other helping professions, genetic counseling sometimes presents as many challenges as it does rewards for practitioners. Given the specialized and sensitive nature of their work, genetic counselors often experience these challenges within the unique contexts of patients' complex medical diagnoses for which treatments are often lacking and subsequent life or death decisions occur.

Effective genetic counseling requires genetic counselors to engage empathically with patients (i.e., put themselves in another's shoes; McCarthy Veach, LeRoy, & Bartels, 2003). When genetic counselors place themselves in the shoes of any of the family members described above, they may ask themselves a variety of questions about the fundamental *meaning* of this situation. For example, they may consider: How do I make *meaning* of such a challenging patient experience? How do (or should) I call upon my personal sense of *meaning* as it has been shaped throughout my lifetime to professionally navigate such complex, emotional, and existential patient journeys? Does my own personal history allow me to empathize more deeply with my patients, thereby strengthening my ability to provide them with the authentic psychosocial support they need? The present study is based on existential philosophical beliefs (cf., Frankl, 1984; Sartre, 2007; Yalom, 1980). Specially, a premise of this current investigation is that personal self-reflection on issues of *meaning* serves as a necessary tool to enhance genetic counseling practice.

Core components of genetic counseling processes and outcomes have long been identified as providing information to patients regarding specific medical diagnoses, fostering their overall adjustment to disorders, promoting understanding of relative risk,

reviewing available treatment options, and supporting patient decision-making (American Society of Human Genetics, 1975). The Genetic Counseling Definition Task Force of the National Society of Genetic Counselors developed a similar definition of genetic counseling as a “process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease” (Resta et al., 2006, p. 77).

Genetic counselors routinely engage with patients and family members who are grappling with larger questions of *meaning* while also making decisions regarding their genetic risk (Biesecker, 2001). Genetic counselors also tend to learn a significant amount about themselves in the process (Runyon, Zahm, McCarthy Veach, MacFarlane & LeRoy, 2010). Their experiences can promote learning outcomes in the form of positive professional development that includes enhanced empathy, strengthened self-esteem, improvement of clinical skills, and the development of expertise (Runyon et al., 2010; Zahm, 2010). Their experiences can also result in negative professional development such as excessive stress, burnout, compassion fatigue, and premature departure from the field (Benoit, McCarthy Veach & LeRoy, 2007; Udipi, McCarthy Veach, Kao, & Leroy, 2008; Zahm, 2010). Factors that determine whether genetic counselors experience positive or negative outcomes, as described above, are relatively unknown empirically, although the counselors’ internal/psychological experiences are speculated to play an integral part.

For example, Witmer, Wedl, and Black (1986) suggest genetic counselors need to learn to deal with the emotional impact of the patient problems they encounter in their counseling, including working through the moral and ethical issues involved in these

contexts. They argue it is imperative for genetic counselors to clarify their own values amidst patient concerns so they can be as objective as possible while helping patients arrive at their own decisions free of coercion, persuasion or bias. Nonetheless, the genetic counseling *gold standards* of value neutrality (van Zuuren, 1997) and non-directiveness (Biesecker, 1998) are the subjects of staunch criticism (e.g., Rentmeester, 2001; Suter, 1998; Toth, Nyari & Szabo, 2008; Wachbroit & Wasserman, 1995). These authors all assert that complete value neutrality likely is impossible for genetic counselors, but that patient autonomy can still be supported as long as the counselors are self-aware regarding their values within sessions and seek out clinical supervision when they recognize their potential influence on patients.

Similarly, Zahm (2010) argues that an essential component of genetic counseling professional development is a deliberate incorporation of self-reflective practice. She defines reflective practice as a lifelong process involving not only the accumulation of direct experiences over time but also a critical examination of those experiences and subsequent changes in one's beliefs and/or actions. Included in this process is the necessary and gradual integration of one's personal and professional selves. While self-reflective practice may often be considered a private activity, or at least done within individual supervision contexts, the benefits of genetic counselor participation in peer group supervision have also been demonstrated empirically (Middleton et al., 2007; Zahm, McCarthy Veach & LeRoy, 2008). These researchers concluded that reflective practice through individual and/or group supervision allows genetic counselors to receive support while approaching their patient cases with authenticity, open-mindedness, and empathy.

Abrams and Kessler (2002) also assert that revealing the “inner world” (p. 5) of genetic counselors is necessary in order to fully understand their total experience. They describe genetic counseling as more than a static communication between providers and patients because it “addresses the nitty-gritty of human dreams and wishes and hopes and the quotidian existence of joy and pain and – for better or worse – it’s based on a relationship between real thinking and feeling people” (p. 16). Consequently, developing a deep understanding of one’s own personal sense of *meaning*, as well as a willingness to explore its potential influence on patients’ worldviews, seems imperative to assuring high quality and effective genetic counseling services.

### **Significance of the Problem**

Some previous efforts have been made to empirically investigate genetic counselors’ beliefs and values in order to better understand the interplay between their personal attributes, professional lessons learned on the job, and professional practice. For example, genetic counselors have been found to highly value constructs such as benevolence, self-direction, achievement and universalism (Pirzadeh, McCarthy Veach, Bartels, Kao, & LeRoy, 2007). In addition, value conflicts have been identified as one of 16 major domains of ethical and professional challenges genetic counselors experience within their work (Bower, McCarthy Veach, Bartels, & LeRoy, 2002; McCarthy Veach, Bartels, & LeRoy, 2001). Consequently, it has been suggested that “[genetic counseling] practitioners must consider multiple, and at times conflicting, ethical principles and professional obligations” (McCarthy et al., 2001, p. 118) in order to work effectively with patients who have genetic concerns.

Runyon and colleagues (2010) found that genetic counselors learn a combination of interpersonal, intrapersonal and professional lessons in their work that include, for example, strong insights regarding their own self-efficacy, the dynamic relationship between their personal and professional experiences, and the need to let go of control (i.e., management of one's values/biases/opinions, acceptance of others' viewpoints, and acceptance that some matters are uncontrollable). Nevertheless, the available findings are based on a handful of studies regarding genetic counselors' beliefs and values at one point in time. Thus their generalizability may be limited. One might postulate that beliefs evolve over time as genetic counselors gain both professional and personal life experience. Consequently, additional research is needed to further understand the potential synergy between personal beliefs and professional practice over time.

Genetic counselors' personal beliefs and values have also been identified through individual interviews, case studies, and essays, in an attempt to develop a deeper understanding of these phenomena. This literature includes accounts regarding genetic counselors' personal and internal lives (e.g., Abrams & Kessler, 2002; Kessler, 1992; McCarthy Veach, Bartels & LeRoy, 2002; McCarthy Veach & LeRoy, 2012; Resta, 2002), as mothers (Anonymous, 2008; Bellcross, 2012; Clark, 2010; McKanna, 2012; Menezes, Hodgson, Sahhar, Aitken, & Metcalfe, 2010), daughters (McCarthy Veach, 2006), students (Bradley, 2012; Burgess, 2012; Infante, 2012; Redlinger-Grosse, 2012), and patients (Anonymous, 2012; Glessner, 2012). However, no empirical work has been done to establish a rich and comprehensive sense of the extent to which genetic counselors experience their own sense of *meaning* within their lives and how this sense has been shaped over time. More specifically, data are lacking about how genetic

counselors develop their sense of *meaning* prior to working within the field and how they both experience and express this *meaning* throughout their work.

Accordingly, the present study was a qualitative investigation of genetic counselors' views of their sense of *meaning* over time. There were four major research questions: (1) How do genetic counselors define a meaningful life for themselves; (2) What specific influences have shaped this sense of *meaning* over time; 3) How do they experience *meaning* within both personal and professional contexts; and (4) What are some particular genetic counseling cases that have challenged and/or reaffirmed their personal views on *meaning*? Analysis of responses to these questions was intended to help elucidate the potentially transformative nature of personal and professional lessons on genetic counselors' sense of *meaning*, how these lessons interface with their clinical practice, and provide further avenues for genetic counseling research and training.

## Chapter 2

### Literature Review

*In some ways, suffering ceases to be suffering at the moment it finds a meaning.*

*(Frankl, 1984, p. 135)*

Although to date, no research has explicitly examined how genetic counselors develop, experience and express a sense of *meaning* as part of their work, this review examines related genetic counseling (and non-genetic counseling) literatures to begin providing a framework in which to understand the importance of issues of *meaning* to the training, supervision, and practice of genetic counseling professionals. First, this review touches on a few of the historical underpinnings of existential thought as they generally relate to the construct of *meaning*, as well as how existential thought has been connected to helping professions such as counseling and psychotherapy. The review then shifts to an examination of the professional development literature (both within and beyond the field of genetic counseling), to argue for parallels between themes such as reflective practice and integration of self with the construct of *meaning*. The review concludes with a deeper look into the genetic counseling literature (both quantitative and qualitative accounts) regarding how practitioners define, approach and experience issues of *meaning* within the contexts of daily clinical practice, professional/ethical dilemmas, challenging patient scenarios, and defining moments throughout their careers.

#### **An Existential Foundation of *Meaning***

In 1959, Viktor Frankl wrote *Man's Search for Meaning* following his experiences as a concentration camp inmate in Germany. In this memoir, Frankl delves into deep descriptions of the committed atrocities within several camps and worked to

make sense of the suffering he both saw and experienced first-hand. These atrocities included neglect, gross mistreatment and murder. Through extensive self-reflection, he came to realize the inherent importance of discovering an underlying sense of *meaning* in one's life experiences, even if those experiences border on horrific. Frankl (1984) further suggests one's life is never made inevitably unbearable by its circumstances alone, but instead becomes unbearable if he or she lacks a sense of *meaning* and/or purpose about one's suffering.

Frankl also argues that the journey to discover a true sense of *meaning* serves as a human being's primary motivation in life, and that one only experiences a deep level of despair if some level of *meaning* is not found. In this regard, he echoes Frederick Nietzsche's famous quote, "He who has a 'why' to live for can bear with almost any 'how'" (as quoted in Frankl, 1984, p. 126). Frankl suggests despair can only begin to be mitigated through active self-reflection and a discovery of *meaning* in one's experience. He also emphasizes there is no single or universal *meaning* in life, each person is responsible for his or her own journey of self-discovery, and the journey is life-long.

Although Frankl was not the first scholar or philosopher who argued that one must establish a sense of *meaning* for his or her suffering (cf., Nietzsche, 1989; Sartre, 2007), this notion eventually became one of the fundamental premises of existential psychotherapy as it is practiced today. Within the resulting framework of Frankl's logotherapy specifically, he suggests profound *meaning* can be experienced in three important ways: "by creating a work or doing a deed; by experiencing something or encountering someone; and by the attitude we take toward unavoidable suffering" (Frankl, 1984, p. 133).

A more contemporary existential author and psychotherapist, Irvin Yalom (1980; 2002; 2008) speaks in similar and illustrative detail about the unique and intimate nature of the therapeutic process and its necessary relationship to the construct of *meaning*. Yalom (1980) is especially known for his postulation of the four ultimate concerns humans possess regarding their existence. The first ultimate concern is *death*. He suggests humans not only have a built-in will to live but also a yearning to thrive during their lives. At some point, however, he suggests we all become aware of our unpredictable but inevitable deaths, and we all experience fundamental anxiety as we work to accept this fact over the course of our lives. The second ultimate concern is *freedom*. Although, on the surface, freedom is often considered an unquestioningly positive experience, Yalom suggests true existential freedom involves a painful realization that we do not exist in a well-defined universe with either a predictable structure or course; and within this amorphous realm, our freedom can cause extreme anxiety through the burden of free will in the face of unlimited choices. The third ultimate concern is *isolation*. This concern involves people's increasing awareness that they both enter and leave the world alone; even when surrounded by flourishing interpersonal social support, our intrapersonal experiences are never fully understood or appreciated by others, and we are alone with our true sense of self. The final ultimate concern is *meaninglessness*. Similar to Frankl, Yalom speaks of the inherent human need for establishing some sense of *meaning* within one's life and the subsequent anxiety we experience when we do not feel we achieve or experience this sense of *meaning*. Yalom further suggests that much of the *meaning* we think we experience on a daily basis might simply be a product of our minds cognitively ascribing a narrative symbolism to

environmental stimuli. In turn, he asserts we all must eventually come to terms with the possibility that we live in a meaningless world.

These four ultimate truths form the basis of Yalom's existential approach to working with therapy clients. He describes the practice of therapy as "a life of service in which we daily transcend our personal wishes and turn our gaze toward the needs and growth of the other" (Yalom, 2002, p. 256). Yalom (2002) also likens the therapeutic process to a "dress rehearsal for life" (p. 182), as counseling provides a space in which clients can begin locating, revealing and accepting the deep and intimate parts of themselves while eventually transferring this personal understanding and experience of *meaning* to their daily lives. He notes that working as a therapist is not only a privilege to share in this *meaning*-making but also that "[leaving] something of ourselves [as therapists], even beyond our knowing, offers a potent answer to those who claim that meaninglessness inevitably flows from one's finiteness and transiency" (Yalom, 2008, p. 83).

Although much of Frankl and Yalom's work describes the existential angst experienced by patients and offers suggestions as to how therapists may serve as helpful guides in their journeys of self-discovery, it must not be assumed patients travel this journey alone. As Starkey (2010) reminds us, "the therapist is an existing human who faces the same existential dilemmas as his or her clients" (p. 8). Yalom (2002) also states, "The active therapist is always evolving, continuously growing in [his or her] self-knowledge and awareness. How can one possibly guide others in an examination of the deep structures of mind and existence without simultaneously examining oneself?" (p.

256). Indeed, Yalom also postulates that one of the greatest benefits a therapist can encounter is learning from and being helped by clients:

We cannot say to them *you* and *your* problems. Instead, we must speak of *us* and *our* problems, because our life, our existence, will always be riveted to death, love to loss, freedom to fear, and growth to separation.

We are, all of us, in this together. (Yalom, 1989, p. 14)

As one can see, working as a counselor with clients engaging in the intimate journey of self-discovery involves the whole range of human emotions; not only privilege and joy but also vulnerability and stress. Farber and Heifetz (1981) similarly note that counselors are “like the shamans and healers of other cultures [who] both prosper and suffer from their calling” (p. 629). Yalom (2002) elaborates on these notions through a personal anecdote about his own work as a psychotherapist:

We are cradlers of secrets. Every day patients grace us with their secrets, often never before shared. Receiving such secrets is a privilege given to very few. The secrets provide a backstage view of the human condition without social frills, role playing, bravado, or stage posturing. Sometimes the secrets scorch me and I go home and hold my wife and count my blessings. Other secrets pulsate within me and arouse my own fugitive, long-forgotten memories and impulses. Still others sadden me as I witness how an entire life can be needlessly consumed by shame and the inability to forgive oneself (p. 257).

The scope of the current review does not allow for a thorough understanding of how a century’s worth of existential literature relates to the ways in which genetic

counselors develop, experience or express *meaning* over the course of their lives. Nevertheless, a consideration of deeply-rooted philosophical frameworks (Nietzsche, 1989; Sartre, 2007), as well as a review of more recent efforts to apply existential themes to therapeutic work with clients (Frankl, 1984; Yalom, 1980, 2002, 2008), will indeed be useful in appreciating the deeper, more substantive connections made by participants in the current investigation when asked big-picture and abstract questions such as: *How do you define a meaningful life for yourself?* Existential theory suggests participants will call upon their personal experiences of suffering and speak to the importance of introspection (and integration) of such experiences to help provide *meaning* to their lives. One may also expect participants will apply some of these same existential themes to their daily clinical practice when describing how the unique and intimate nature of their work helps instill a deep sense of personal and professional *meaning* over time.

### **Professional Development within Counseling and Psychotherapy**

In order to further understand the importance of *meaning* (i.e., its development, experience and expression) within the lives of genetic counselors specifically, one must also consider a review of published literature on the topic of professional development, in which the construct of *meaning* is consistently referenced, if not named directly. As extant literature on this topic, within the field of genetic counseling, is scarce, however, it is helpful to first selectively review the broader literature to more fully appreciate the phenomenon. Although many theories of professional development have been offered across various disciplines (cf. Ducheny, Alletzhauser, Crandell, & Schneider, 1997; Lindley, 1997; Mitchell, 2001; Postle, Edwards, Moon, Rumsey, & Thomas, 2002), this literature review begins within the related field of psychotherapy (i.e., Jennings &

Skovholt, 1999; Moss, Gibson, & Dollarhide, 2014; Orlinsky et al., 2005; Ronnestad & Skovholt, 1992, 2003), and is followed by a review of two recent genetic counseling dissertations (i.e., Miranda, 2012; Zahm, 2009).

In 2005, Elman, Illfelder-Kaye, and Robiner were recruited as a special task force by the American Psychological Association to provide a comprehensive definition of professional development for practicing psychologists. Their extensive review of the relevant counseling and psychotherapy literature included both self-reports of career identity development and supervisor descriptions of trainee development. These authors created the following definition in order to help begin describing the comprehensive tasks inherently involved in counselors' professional development over time:

Professional development is the developmental process of acquiring, expanding, refining, and sustaining knowledge, proficiency, skill, and qualifications for competent professional functioning that result in professionalism. It comprises both: a) the internal tasks of clarifying professional objectives, crystallizing professional identity, increasing self-awareness and confidence, and sharpening reasoning, thinking, reflecting, and judgment; and b) the social/contextual dimension of enhancing interpersonal aspects of professional functioning and broadening professional autonomy (p. 368).

The various components of this definition imply that professional development is viewed as continually shifting and evolving over time. Professional development not only involves gaining the necessary knowledge required for particular job duties, it also involves gaining specific skill sets, proficiency and a strengthened professional identity.

Understandably, professional development requires internal activities such as increased self-reflection and insight. Nevertheless, it also unquestioningly occurs within a social framework of the overall profession including specific training modalities, supervisors/mentors, colleagues, and overarching professional attitudes.

Skovholt and Ronnestad (1992) published an initial model of practitioner development that encompasses the qualitative experiences of therapists across their professional lifespans. Using a longitudinal and cross-sectional design, these authors interviewed 100 therapists in a mid-Western state who ranged from beginning/novice counselors to those already in retirement. Evaluating participant responses to questions regarding their thoughts, behaviors, and personal processes as they have occurred throughout their careers, the authors initially created an eight-stage model that they eventually altered to reflect a six-stage model of professional development approximately one decade later (Ronnestad & Skovholt, 2003). These six stages include lay helper, beginning student, advanced student, novice professional, experienced professional, and senior professional. These authors argue that at each stage development tends to involve some major task in a predictable sequence, although they also emphasize this sequence is not always steadfast or linear and that it should instead be considered flexible in nature and/or at least somewhat recursive. For example, within the novice professional phase, a common task is to embrace the newfound freedom after having completed graduate school, as well as confront the disillusionment that tends to occur when counselors realize their educational and clinical training fall short of providing answers and/or specific direction in complicated and ambiguous clinical scenarios.

Using inductive analysis of interviewees' responses, Ronnestad and Skovholt (2003) extracted fourteen themes that represent the therapist's overall professional development over time. Similar to the flexible progression through the six stages described above, the individual themes do not directly correspond to each individual stage but instead represent underlying connections across the stages. While the entire list is too extensive to review in detail here, several specific themes appear particularly relevant to that field of practice as well as this dissertation's focus on genetic counselors' personal experiences of *meaning* within their work.

First, Ronnestad and Skovholt (2003) identified that counselor professional development involves an increasingly higher order integration of the professional self and the personal self. In other words, therapists are not only able to recognize the unique contributions of their personal experiences (including preferences, beliefs, values, and attitudes outside of work) and their professional experiences (including strategy/skill development and competency-building), they also that learn all of these experiences are intimately connected and experience a greater sense of integrity when gaps or inconsistencies between these two realms are eliminated. For example, Ronnestad and Skovholt (2003) provided an example of clinicians adapting their theoretical orientation over time not only because they have found it particularly ineffective with particular clients, but also due to some "significant or transforming event in their personal lives" (p. 28). In addition, the authors emphasized that clients serve as critically important teachers, and extensive exposure to client stories of suffering can contribute to counselors' heightened awareness and general appreciation of constructs such as pain, resilience and individual differences.

Jennings and Skovholt (1999) found similar results as they relate to the realm of expert therapists, especially with regards to multicultural diversity and cultural competence. Based on the assumption that therapists' personal characteristics necessarily inform the therapeutic alliance with clients, these authors hypothesized, not only is it "useful to understand more fully the qualities [that] effective therapists bring to their work" (p.3), but also the personal and professional characteristics that combine to produce expertise within the field. To begin, Jennings and Skovholt (1999) used a purposeful "snowballing" method of recruitment within an upper-Midwest metropolitan area, by asking their own professional peers to nominate colleagues who were the "best of the best" (p. 4) in the field. They ultimately interviewed 10 participants ranging in age from 50-72, with clinical experience ranging from 21 to 41 years, regarding their personal characteristics, career growth, perceptions of the general construct of expertise, and their own expertise specifically.

Responses were qualitatively analyzed and organized into three general domains: cognitive, emotional, and relational. Cognitively, master therapists were found to practice as voracious learners, call upon their accumulated life and work experiences in their practice, appreciate ambiguity and value cognitive complexity. Emotionally, master therapists tended to be emotionally receptive (i.e., self-aware, reflective, non-defensive, and open to feedback), mentally healthy/mature, and aware of their emotional health effects on their professional work. Relationally, master therapists tended to have strong interpersonal skills, possess beliefs about human nature that help build strong working alliances, and be especially skilled at the "art of timing, pacing and dosage" (p. 8) with their relationally-based interventions.

These findings have been replicated in a number of studies (Jennings, Goh, Skovholt, Hanson, & Banerjee-Stevens, 2003; Skovholt & Jennings, 2004; Sullivan, Skovholt, & Jennings, 2004; Jennings, Sovereigh, Bottorff, Mussell & Vye, 2005; Jennings et al., 2008). Collectively, these researchers have ultimately demonstrated that years working in a field do not necessarily translate into levels of expertise, and personal experiences of the practitioner matter, as do their personal characteristics (e.g., regular self-reflection and a constant striving for self-improvement).

Although the present study did not set out to define master genetic counselors, its purpose was to gain a fuller understanding of the personal characteristics genetic counselors bring to their work as well as their experiences of *meaning* over the course of their careers. Jennings and Skovholt's (1999) findings that master therapists call upon their accumulated life and work experience helped inspire the current inquiry into how genetic counselors engage in similar processes even prior to entering the field. In addition, these authors' findings that master therapists are self-aware, self-reflective, and sensitive to how their emotional health affects their professional work, have collectively informed the current investigation with respect to how these same phenomena play out within the daily work of genetic counselors.

Orlinsky and colleagues (2005) also attempted to describe professional development of counselors throughout the lifespan, but used primarily quantitative methods versus the sole interview approach of Ronnestad and Skovholt (2003). In a sequence of studies, these authors administered the "Development of Psychotherapists Common Core Questionnaire" (*DPCCQ*; 1991), a paper-based survey to gather data from psychotherapists across a number of sub-disciplines around the world (Orlinsky et al.,

1999; Orlinsky, Botermans, Ronnestad, & the SPR Collaborative Research Network, 2001) on a range of topics. Examples of questions from the DPCCQ include: How much mastery do you have of the techniques and strategies involved in practicing therapy?; How much do you feel you are changing as a therapist?; and How much do you feel you are deepening your understanding of therapy? This research group then presented aggregate factor-analyzed findings for over 5,000 practitioners across profession, nationality and theoretical orientation, within a comprehensive project entitled *How Psychotherapists Develop: A Study of Therapeutic Work and Professional Growth* (Orlinsky et al., 2005). With their findings, Orlinsky and colleagues (2005) have helped describe how therapists tend to develop over time, how both positive and negative contexts specifically impact their development, and how such development influences both their personal and professional lives. For example, some of the contexts the researchers explored with participants were: technical skills gained, identifying and overcoming personal limitations, experiencing enthusiasm, “losing capacity to respond empathically,” and even becoming “disillusioned about therapy” (p. 110).

While Orlinsky et al.'s (2005) overall book-length findings are too expansive to be reviewed in detail here, the participants' perceived sources of influence on their professional development are very relevant to the current study. In descending order of frequency, the top perceived influences were identified as: “(1) experience in therapy with patients; (2) personal therapy, analysis, or counseling; (3) getting supervision or consultation; (4) taking courses or seminars; (5) experiences in personal life; (6) informal case discussion with colleagues; (7) reading relevant books or journals; (8) working with co-therapists; (9) teaching courses or seminars; (10) institutional conditions of one's

practice; (11) observing other therapists; (12) doing research; and (13) ‘other’” (p. 127). The ordering of this list suggests interpersonal influences (both personal and professional) tend to have stronger (or at least more memorable) effects on practitioners throughout their careers compared to more traditional and/or academic contexts such as taking courses and reading journal articles. In addition, a majority of participants (approximately 60%) described their personal life experiences as having a strong positive influence on their professional development, while a much smaller number (i.e., 5%) described their personal life experiences as having a negative impact. This marked difference might partially be due to self-selection into the study; that is, individuals with more positive experiences as a therapist may have wanted to share those experiences with the researchers.

Interestingly, Orlinsky et al. (2005) found that therapy experiences with patients were the “strongest and most widely endorsed positive influence[s]” (p. 127) on the participants’ development. In addition, those participants who were in therapy themselves tended to show the “highest rate of progress” (p. 121) in strengthening professional development. Together, these findings suggest both interpersonal and intrapersonal sources serve as particularly strong influences on how practitioners experience a sense of *meaning*, as well as how they develop as competent professionals over time. They also suggest consistent and meaningful interactions as both therapist and client can produce a level of increased reflection, insight and integration of professional identity throughout one’s career.

Orlinsky et al.’s (2005) impressively large sample included professionals who worked with a wide range of clients in diverse settings and employed a variety of

theoretical perspectives in their practice. In addition, their very large/international sample and diverse sampling procedures across studies strengthen the generalizability of their results. Nevertheless, their conclusions are tempered by exclusive reliance on self-report data and the lack of in-depth analysis of participants' responses to open-ended questions to identify thematic patterns.

A more recent model of professional development within the field of counseling has been offered by Moss et al. (2014) and deserves mention. The researchers used stratified purposeful sampling of school and community-based counselors through a state mailing list as well as local school district contacts. Twenty-six individuals participated in focus groups formed on the basis of years of experience within the field and specific area of practice. The researchers asked the participants questions concerning how they generally defined their practice of counseling, how they defined their sense of professional identity at that time, and the types of tasks they thought might be necessary in order to progress to the next level of professional development.

Using grounded theory to analyze the focus group data, Moss et al. (2014) found three primary themes involving transformational movement of one's sense of professional identity over time: 1) adjustment to expectations; 2) confidence and freedom; and 3) separation versus integration. Transformational tasks involving adjustment to expectations (and general attitude towards one's work) often included movement from a sense of idealism to a sense of realism, such as coming to realize that one is merely a facilitator (rather than the sole agent) of change for a client. Transformational tasks involving confidence levels (and general energy towards one's work) included movement from an experience of burnout to an experience of

rejuvenation. Specifically, clinicians might come to terms with how their clinical practice does not exactly align with their education/training and, therefore, work to find ways to draw positive energy from the unpredictability of their work over time. Transformational tasks involving an integrated sense of professional identity included movement from a state of compartmentalization to a state of congruency, where one begins to integrate his or her individual skills and competencies into a solid professional identity.

Moss et al. (2014) also found three additional themes that collectively serve as common catalysts for movement within each of the above described domains: 1) experienced guides; 2) continuous learning; and 3) work with clients. In other words, having experienced supervisors/mentors/colleagues, maintaining a commitment to sharpening knowledge and skills throughout one's career, and meaningful interactions with individual clients, all spark the aforementioned transformational tasks to move a practitioner from an experience of primarily external validation and isolation to self-validation and a stronger sense of professional identity over time. Similar to Ronnestad and Skovholt (2003) and Orlinsky et al. (2005), these authors suggest one of the most important implications of their findings is providing counselors with a process-view of their professional identity development that helps normalize their experiences, reinforces the importance of working through personal struggles via peer-support and direct clinical supervision, and inspires a perspective of life-long learning.

The above review of the professional development literature within the broader field of counseling and psychotherapy provides a useful foundation for considering how clinicians develop over time. Although this literature rarely provides explicit examples or discussion for how practitioners develop or experience a personal sense of *meaning*

within their work per se, such a process is consistently implied. As Elman, Illfelder-Kaye, and Robiner (2005) offer with their generally-accepted definition of professional development for practicing psychologists, clinicians not only acquire specific skills and competencies throughout their careers, they also engage in important meaningful interpersonal contexts with clients and coworkers, as well as internal tasks such as clarifying values and strengthening their own self-awareness. Skovholt and Ronnestad (1992) and Ronnestad and Skovholt (2003)'s efforts similarly speak to the importance of integrating one's personal and professional selves over time (i.e., reflection and resolution of personal beliefs, attitudes, preferences, values and skills). They also argued this process is life-long and often non-linear in nature. Jennings and Skovholt's (1999) work provides a number of examples for how one develops expertise within the field of psychotherapy as well, including: committing oneself to life-long learning; consistently calling upon one's personal experiences to inform clinical practice, developing an appreciation of ambiguity inherent to their nuanced work, and becoming increasingly emotionally-receptive and self-aware. Finally, the more recent work of Moss et al. (2014) describes professional development for counselors as involving specific catalysts (e.g., seasoned mentors, continuous learning, and memorable experiences with clients) for transformational movement within areas of personal adjustment, increased confidence and a sense of identity integration throughout one's career. These researchers also argued for the importance of educating counselors with this process-view to help normalize anxieties common to initiating their work, reinforcing the importance of supervision and consultation, and inspiring a commitment to learning and identity integration. These ideas

are re-visited later in this paper to ground participants' insights regarding their development and experiences of *meaning* within this professional development literature.

The following section describes two similar, and recent, efforts to examine how professional development occurs within the field of genetic counseling. Again, as the specific construct of *meaning* is rarely discussed explicitly within this literature, direct inferences pulled from the *meaning*-related ideas of professional identity development, reflective practice and self-integration are appropriate.

### **Professional Development within Genetic Counseling**

To date, Zahm (2009) is the only author who has attempted to critically examine and provide a comprehensive model of professional development specific to genetic counselors. Her dissertation study involved individual interviews with 34 practicing genetic counselors from the United States and Canada. Interview questions asked about the components and processes of their professional development over time, including facilitators and barriers to this development. She also looked for thematic differences due to experience level. Using a modified version of Consensual Qualitative Research (CQR) methodology (Hill et al., 2005), she identified three descriptive themes, 12 domains and 46 categories. Zahm also structured her results as a direct comparison to Ronnestad and Skovholt's (2003) and Orlinsky et al.'s (2005) professional development models described earlier in this chapter, and she concluded her findings are strongly congruent with those prior models.

Zahm's (2009) first theme entitled "Being a clinician: Genetic counselors' evolving perceptions of and relationships to their clinical work" pertains to participant descriptions about how these perceptions and relationships tend to change over time. This

theme includes participants' views on the components of helping (e.g., education, resources, and emotional support), how they define success with patients, the types of challenges they experience with patients (e.g., difficult patient feelings/expectations, uncertainty/ambiguity, and their own personal, strong emotional reactions), and particularly memorable patients (especially as they relate to experiencing the fragility of life), and these patients' effects on them personally.

Within this theme, Zahm found the longer genetic counselors practice in the field, the less idealistic (and more realistic) they become in their expectations regarding practice outcomes and their ability to truly help patients. Furthermore, although participants from all experience levels noted profound lessons and intense experiences with their patients, it also seemed that those with more professional experiences (and personal experiences outside of work) had a greater number of ways to conceptually connect these experiences and extract *meaning* from them. This finding is particularly noteworthy, as self-reflection has been described as a critical component to professional development across disciplines (e.g., Jennings & Skovholt, 1999; Orlinsky et al., 2005; Ronnestad & Skovholt, 2003).

Zahm's (2009) second theme is entitled "Views of the profession: Genetic counselors' evolving perceptions of and relationships to the field of genetic counseling." There was a wide variety in responses to practitioners' views on the field as a whole, with some greatly appreciating the professional tasks/expectations and others feeling concerned about the rapid pace of changes within the profession. Nevertheless, most participants expressed a general hope that the profession would become stronger and more integrated over time.

Zahm's (2009) third theme, entitled "Being a clinician within the profession: Genetic counselors' evolving perceptions of and relationships to their professional identity" involves how genetic counselors' sense of professional identity is influenced throughout their careers. Participants' described their current motivations to practice genetic counseling (e.g., the importance of relational experiences with patients and coworkers), their definitions of professional development (e.g., growth in competencies), goals of professional development (e.g., self- and other-focused professional tasks), specific catalysts for professional growth (e.g., job and role shifts), the effects of their personal lives on their professional development (e.g., increased self-reflection and effects on empathy for patients), and varying levels of career satisfaction. This third thematic area is highly consistent with most of Ronnestad and Skovholt's (2003) levels of professional development as described earlier in this chapter. For example, areas of strong overlap between these two studies include: most novice clinicians experience anxiety regarding their work and master this over time; clients serve as primary teachers; and extensive exposure to human suffering contributes to increased awareness, acceptance and appreciation of human variability.

Overall, Zahm's (2009) findings provide an initial foundational understanding of professional developmental processes within the field of genetic counseling. Although her study is the first of its kind within this specific field of practice, her findings seem credible due to the coherent connections the author made with previously established models of professional development within other disciplines. In addition, it seems especially relevant to the current investigation that the genetic counselors in Zahm's study discussed how integrating more of their own personality traits and communication

styles (as well as their personal beliefs and values) into their work with patients have resulted in an enhanced sense of professional development. Similarly, these genetic counselors also explained that with a commitment towards self-reflection, meaningful experiences in their personal lives have resulted in a deeper understanding of themselves, as well as strengthened work-life balance, increased self-care and enhanced boundary-setting. Again, although not explicit, the connection between these themes and the current investigation's exploration of the experience of *meaning* seems strong. Calling upon one's personal beliefs and values, as well as a commitment towards self-reflection and an integrated sense of self, will likely serve as foundations for participant responses when asked questions regarding how they define a meaningful life for themselves, lifetime sources of influence on that sense of *meaning*, work-related contexts that challenge and/or reaffirm that sense of *meaning*, and how that sense of *meaning* has changed over time.

Zahm (2010) also extended this discussion of the importance of self-reflective practice in her book chapter entitled, "Professional Development: Reflective Genetic Counseling Practice." In this chapter, she advocates for the deliberate incorporation of reflective practice as an essential component of genetic counselor professional development. She defines reflective practice as a lifelong process involving not only the accumulation of direct experiences over time but also a critical examination of those experiences and subsequent change in one's beliefs and/or actions. Included in this process is the necessary and gradual integration of one's personal and professional selves. Zahm offers several pragmatic suggestions for fostering a reflective process over the course of one's career through didactic training, clinical supervision, peer-group

supervision, sharing of stories, and an early integration of self-reflection into daily practice.

Zahm (2010) also argues it is imperative that genetic counselors approach their work with a commitment to reflective practice in large part due to the concerning trends of burnout and compassion fatigue within the field. While burnout (a tendency to feel overworked, overwhelmed and exhausted) is common within the context of many helping professions such as medicine (McManus, Keeling, & Paice, 2004), nursing (Payne, 2001) and mental health (Rossi et al., 2012), genetic counselors have been shown to rank significantly higher in emotional exhaustion than both social service and mental health workers (e.g., Dexter, Mahoney, Schrag-Wang & Rintell, 2003). In addition, compassion fatigue (an acute and often sudden feeling of being overwhelmed by empathic connections with client suffering) is particularly real and palpable within the field of genetic counseling while working from a supportive role with patients on complex medical diagnoses and life or death treatment decisions (e.g., Benoit, McCarthy Veach, & LeRoy, 2007; Injeyan et al., 2011; Lee, McCarthy Veach, MacFarlane, & LeRoy, 2014; Udipi, McCarthy Veach, & LeRoy, 2008).

Of note, Zahm's (2009) research directly relates to the present study, as many of her domains and categories have direct implications for how genetic counselors may define and/or experience *meaning* and purpose over the course of their careers. For example, participants in her study certainly referenced specific contexts within their daily clinical work that influence a sense of satisfaction such as intimate/memorable patient experiences, and turning points within one's career. While most of these experiences likely occur primarily within daily clinical practice Zahm emphasized they are rarely, if

ever, experienced in isolation from one's personal sense of self or the sets of attitudes, beliefs, and values that one brings to his or her clinical work. While many of Zahm's (2009) participants tended to offer relevant and personal examples for how they experience *meaning* within their work at a particular point in time, the purpose of the current investigation was to establish a more comprehensive understanding of how genetic counselors' overall sense of *meaning* has been influenced historically. In other words, the current investigation not only examined how genetic counselors experience their own personal sense of *meaning* presently, but also prior to and outside of their clinical practice.

In another qualitative genetic counseling study, Miranda (2012) explored the personal and professional characteristics of expert genetic counselors, that is, those individual considered masters within the field. Using a peer-nomination approach (similar to Jennings & Skovholt, 1999) to identify those considered the best at what they do, Miranda invited 54 leaders in the field of genetic counseling to nominate potential participants. Those leaders were asked to consider colleagues who they would offer as a referral to a friend or family member due to their particular competency/expertise, who they would feel comfortable seeing for their own genetic counseling, or whom they would consider to be among the "best of the best" of genetic counselors (p. 82).

Miranda (2012) then interviewed a sample of 15 genetic counselors to explore their personal characteristics (including motivations and inspirations), their strengths and struggles throughout the course of their careers, and general views of their professional development. She used a modified version of CQR (Hill, 2012) to analyze participants' responses, and extracted four broad themes related to: 1) personal characteristics of the

genetic counselors themselves; 2) relationships with their patients; 3) beliefs regarding success; and 4) overall views of the profession.

Miranda (2012) identified 10 specific characteristics of master genetic counselors. Overall, masters in the field seem to have an “insatiable curiosity” (p. 108) and commit themselves to life-long learning. They tend to be self-reflective, self-aware, and confident, yet also humble. They seem to be authentic in nature and call upon their personality styles to inform their counseling styles. They are skilled at considering the nuanced complexity of the counseling process and form collaborative and engaging relationships with patients. Master genetic counselors struggle when they feel a lack of connection with their patients. They are indeed affected emotionally by their work but also tend to have diverse coping mechanisms for managing their emotional stress. They tend to have a deep sense of empathy that fuels their practice and they often feel rejuvenated by their work. Finally, Miranda (2012) found master genetic counselors have widely ranging perspectives on the nature, process and development of the profession itself.

Major strengths of Miranda’s (2012) dissertation findings include their congruence with Zahm’s (2009) results concerning the professional development of genetic counselors, and their identification of particular characteristics of optimal development for genetic counselors. Of note, Miranda’s findings hold up to a cross-examination with similar approaches to identify the traits of master clinicians within other fields of practice such as social work (e.g., Fook, Ryan, & Hawkins, 2000), physical therapy (e.g., Jensen, Gwyer & Shepard, 2000) and nursing (e.g., Benner, 2000; Benner, Tanner, & Chesla, 1992). In addition, Miranda’s (2012) sample included some

gender and multicultural diversity.

As with any qualitative research, it is entirely possible that the subjective responses of Miranda's (2012) interviewees are idiosyncratic and context-dependent. Moreover qualitative data are not intended to be generalized to the population of interest. Data based exclusively on self-report may be biased if participants wish to present themselves in a favorable light. This particular limitation appears especially plausible in a study asking participants to describe what makes them so good at what they do. Finally, only six of the initial leader-nominators responded to the researcher's invitation to nominate individuals for the study sample.

Despite these limitations, Miranda's (2012) findings are particularly relevant to the current study. First, although she did not explicitly ask participants to describe what is inherently meaningful to them as individuals, their responses provide rich descriptions of what they perceive as important components to their personal and professional development. It appears both relevant and appropriate to infer genetic counselors' personal perceptions of overall *meaning* from responses to questions regarding personal motivations, inspirations, and what makes them good at what they do. The findings further suggest there are indeed rich sources of *meaning* behind one's optimal development as a genetic counselor, and in order to fully understand those sources of *meaning*, one must consider interpersonal, intrapersonal, and some existential (e.g., freedom and meaninglessness) factors.

The above review of the extant genetic counseling literature regarding professional development (based on the earlier review of non-genetic counseling literature) adds to an initial understanding of how a construct such as *meaning* might be

experienced within one's clinical practice with patients over time. In the first known empirical effort to provide a comprehensive definition of professional development within the field of genetic counseling, Zahm (2009) found genetic counselors tended to experience intense and profound lessons from direct interactions with their patients (often based on patients' suffering and related resilience), called upon their own personal lives to inform their work with patients (such as increased empathy), developed sophisticated ways to conceptually connect their individual experiences to pull *meaning* from them, and developed a strengthened/integrated sense of self over the course of their careers. These findings are largely congruent with those of Ronnestad and Skovholt (2003) and Orlinsky et al. (2005). Miranda (2012) extended these findings in an empirical investigation of the development of expertise within the field of genetic counseling. Similar to Jennings and Skovholt (1999), she found genetic counselors tended to have deep levels of curiosity and a value for life-long learning. She also argued expert genetic counselors are indeed affected emotionally by their challenging work, but they also develop more diverse coping mechanisms in the face of adversity compared to novice practitioners. And finally, Miranda (2012) suggested one sign of genetic counselor expertise is authenticity within one's practice, as well as an ability to call upon one's own personality style to help shape his or her counseling style with patients.

Again, these ideas will be re-visited later in this paper as a means to ground genetic counseling participant responses in the present study regarding their personal sense of *meaning* within the established professional development literature as described above, both within and beyond the field of genetic counseling. Continuing with a review of the available genetic counseling literature, the next section now shifts from a broad

view of professional development to a deeper exploration into how specific issues of *meaning* arise within the scope of daily clinical practice.

### **Genetic Counseling Practice and Issues of Meaning**

The core components of the genetic counseling process have long been identified as providing information regarding specific medical diagnoses, fostering overall adjustment to disorders, promoting understanding of relative risk, reviewing available treatment/decision options and supporting patient decision-making (American Society of Human Genetics, 1975). Resta and colleagues (2006) also provided an updated peer-reviewed definition of the field that speaks to the “process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease ... [through] interpretation ... education ... and counseling to promote informed choices and adaptation to the risk or condition” (p. 77).

A number of psychological aspects have been identified as integral to the professional practice of genetic counseling as well. For instance, Witmer, Wedl and Black (1986) suggest these psychological aspects include genetic counselors themselves learning to deal with the emotional impact of the problems addressed in counseling and working through the moral and ethical issues involved in these contexts. They further state that “because genetic counseling deals with the interplay of the sanctity of life and quality of life issues, the competency and ethical awareness of the counselor are of the utmost importance” (p. 339). Consequently, they argue it is imperative for genetic counselors to clarify their own values within the context of patient concerns so they can be as objective and neutral as possible while helping patients arrive at their own decisions free of coercion, persuasion or bias. In this sense, unless genetic counselors maintain

neutrality with regards to their own personal belief and value systems, patient autonomy might be compromised while making life-altering decisions such as genetic screening, informing relatives of their condition, and terminating a pregnancy due to a fetal anomaly.

Nonetheless, these genetic counseling *gold-standards* of value neutrality (van Zuuren, 1997) and supporting patient autonomy through non-directive approaches (Biesecker, 1998) have been the subjects of recent and staunch criticism (Rentmeester, 2001; Suter, 1998; Toth, Nyari & Szabo, 2008; Wachbroit & Wasserman, 1995). In fact, Wachbroit and Wasserman (1995) argue that value neutrality in genetic counseling is impossible due to autonomy itself being a value, which if honored by genetic counselors, cannot be held neutral. Nevertheless, the authors assert that patient autonomy may indeed still be supported by genetic counselors who are not altogether neutral in their personal values, as long they are self-aware regarding these values when they arise in sessions and seek out clinical supervision when they recognize their potential influence on patients.

When one considers the experience of *meaning* within one's clinical practice, it is also important to consider the sense of well-being and/or satisfaction one has for the work itself. As part of an initiative to continuously monitor trends within the field of genetic counseling, the National Society of Genetic Counselors (NSGC) publishes results of its Professional Status Survey every two years, and inquires about its members' basic demographics and work-specific information (e.g., geographic region of practice, specialty area, salary, and general satisfaction with their current position). Of note, while a strong majority of respondents (87%) in the 2006 survey (Parrott & Del Vecchio, 2006)

reported that they were satisfied with their personal growth within the profession, only 65% reported feeling satisfied with their overall professional growth within the field. In addition, 15% of the respondents indicated that they were considering leaving the profession at the time they took the survey, with just under half of those respondents citing “burnout” as a primary contributing factor. While the strictly quantitative nature of the Professional Status Survey only allows for speculation regarding the rationale for these numbers, the latter report of dissatisfaction with the field has sparked great interest, concern and further inquiry into the individual and/or personal experiences of genetic counselors that might inspire such a response (Benoit et al., 2007; Injeyan et al. 2011; Lee et al., 2014; Udipi et al., 2008).

**A model of genetic counseling practice.** McCarthy Veach, Bartels and LeRoy (2007) convened a consensus conference within the NSGC for the purpose of generating an empirically-based descriptive model of genetic counseling practice. Twenty-three program directors or their representatives from genetic counseling graduate programs in North America engaged in presentations and participated in focused group discussions regarding the components of genetic counseling they deemed most integral to genetic counseling practice. Based on their comments, extant literature, and the researchers’ own experiences, McCarthy Veach et al. (2007) proposed a descriptive model of genetic counseling practice, coined the Reciprocal-Engagement Model (REM).

The REM consists of a “mutual process in which the genetic counselor and patient participate in an educational exchange of genetic and biomedical information shaped by their unique psychosocial identities” (McCarthy Veach et al., 2007, p. 726). The authors visually represent this model as a triangle with *education*, *individual*

*attributes* and *genetic counseling* as the three respective points and the genetic counselor-patient relationship at its center. Five important tenets (fundamental assumptions) underlie the model: 1) genetic information is key (under *education*); 2) relationship is integral (at the center under *relationship*); 3) patient autonomy must be supported (under *individual attributes*); 4) patients are resilient (under *individual attributes*); and 5) patient emotions make a difference (under *individual attributes*).

Conveying specific genetic information as a means to educate patients has long been considered one of the most important tasks of a genetic counselor (Stern, 2009). In order to convey accurate information that is comprehensible to patients, genetic counselors must assess personal histories, background, particular risk and specific needs. This presentation of information contributes to patients' abilities to make informed decisions, manage their conditions, and adapt to their situations.

The relationship between provider and patient is also considered as central to the process of genetic counseling based on the assumption that people need human connection and that such connection is the crucial vehicle for delivering the desired genetic information. Not only are a strong working relationship, rapport and communication necessary for the relationship between a genetic counselor and patient to be effective, but genetic counselors also need to be "reflective practitioners, who are self-aware, ethical, objective to the extent possible, and open and responsive to feedback" (p. 721).

The latter three REM tenets reference patients' individual attributes. First, patients are assumed to know themselves best and are therefore, assumed to be self-directive regarding decisions made as part of their involvement in genetic counseling. Patients

also are assumed to be resilient, possessing sufficient strength and personal resolve to deal with challenging situations. Finally, patient emotions make a difference. More specifically, their emotional states can greatly influence their desire for genetic information, their willingness to connect with genetic counselors, their comprehension of information, the emotional impact of that information, their desire for autonomy, and their own perceived resilience.

McCarthy Veach et al. (2007) assert the above-described REM tenets mutually influence each other, and no tenet can be wholly understood on its own. As envisioned, the REM of genetic counseling practice necessarily taps into patients' intrapersonal, interpersonal, and cultural identities as well as the personal characteristics of genetic counselors themselves (e.g., values, biases, ethics, etc.).

Although the REM (McCarthy Veach et al., 2007) is used primarily to inform a standard of genetic counseling practice, systematically train new genetic counselors, and evaluate the effectiveness of service provision, it holds strong relevance to the current study of the construct of *meaning* as well. As the authors suggest, it is critical for practicing genetic counselors to take a self-reflective approach to their work in order to increase self-awareness, appreciate their strengths and weaknesses, and understand how their own views on *meaning* (e.g., thoughts, emotions, beliefs, values) influence not only their patients' experience of the service but also potentially the overall genetic counseling outcome as described by the REM.

**Ethical challenges and *meaning* in genetic counseling practice.** Researchers have attempted to move beyond correlational and survey designs in order to investigate the specific types of major ethical and professional challenges healthcare professionals

experience when working with patients who have genetic concerns. For instance, McCarthy Veach, Bartels, and LeRoy (2001) asked this very question in 12 focus group interviews with genetic counselors, nurses, and physicians ( $N = 97$ ) in four major geographic areas (East Coast, West Coast, Midwest, and Southeast). They explored participants' perceptions of what is meant by ethical/professional challenges; the most frequently encountered ethical/professional challenges either they or a colleague have faced when their patients have genetic concerns; particularly difficult ethical/professional challenges either they or a colleague have experienced in their practice when their patients have genetic concerns; resources they turn to for guidance with these ethical/professional challenges; and issues regarding how to appropriately refer patients who have genetic concerns (p. 100). The researchers used CQR (Hill, Thompson & Nutt-Williams, 1997) methods to analyze participant responses.

McCarthy Veach et al. (2001) identified sixteen major domains of ethical and professional challenges ranging from issues related to informed consent, documentation, confidentiality, determining the primary patient, resource allocation and professional misconduct, among others. One of the domains (most relevant to this current study) is *value conflicts*, which includes three categories of intrapersonal (i.e., internal conflict within the genetic counselor), interpersonal (i.e., conflict between a genetic counselor and either patients, colleagues or society) and extrapersonal value conflicts (i.e., conflict between others' such as between patients' family members). Participants' responses range from concern to "moral outrage" (p. 112) regarding the various scenarios they have encountered in their daily work. The authors found this domain to be somewhat thematically connected to another domain of *directiveness/nondirectiveness* in that the

clinicians tended to be more comfortable (and thereby less directive) with patients' decisions when they were in line with the clinicians' own personal values, which often included the prevention of suffering and enhancement of health. The researchers concluded that "practitioners must consider multiple, and at times conflicting, ethical principles and professional obligations" (p. 118) while working with patients who have genetic concerns.

Other ethical and professional domains identified by McCarthy Veach et al. (2001) are *facing uncertainty*, *professional identity issues*, and *emotional responses*. Regarding *facing uncertainty*, the professionals often found themselves struggling with ethically navigating situations that involve uncertainty of long-term outcomes, limited information, lack of guidelines, patient indecisiveness, and occasional concerns about how useful and/or meaningful information will actually be for patients. Regarding *professional identity issues*, the participants spoke of often feeling great uncertainty about their professional roles, feeling conflicted with dual, blurred or conflicted relationships, and feeling caught in the middle (i.e., torn between competing wishes of patients, colleagues or supervisors). Regarding *emotional responses*, the participants spoke of their personal struggles to deal with intense affect experienced within sessions in the areas of communicating bad news, responding to patients' intense emotions, effectively managing their own elicited emotions, and emotional distress prompted by the delivery of the genetic information itself.

McCarthy Veach et al. (2001) provided a comprehensive summary and analysis of all 16 major ethical and professional challenges from their study. Although an extensive review of the 16 domains is beyond the scope of the present literature review,

the authors did offer a few recommendations for the four relevant domains described above. Regarding *value conflicts* (often centered on issues related to supporting patient autonomy, enhancing health and/or preventing suffering), the authors encouraged genetic counseling professionals to work towards an increased awareness of their own personal values with the assumption that such awareness will reduce the likelihood of unnecessarily directive approaches to counseling. For the other three domains described above, the authors emphasized the importance of good mediation skills, practiced tolerance for difficult patient affect, and a willingness to refer patients for additional assistance for counseling services as appropriate. They also encouraged genetic counseling professionals to seek consultation with colleagues to navigate professional identity issues.

One limitation of McCarthy Veach et al.'s (2001) study includes their use of a nomination sampling method, likely decreasing representativeness of the sample. The qualitative nature of focus group discussions, although allowing for elicitation of rich descriptions, also precludes strong generalizations to the populations of interest. In addition, the authors pointed out that in this type of research, frequency of certain domains does not necessarily imply importance (Krueger, 1994).

Nevertheless, McCarthy Veach et al.'s (2001) results appear credible in that they nicely align with each of the professional groups' codes of ethics and are largely consistent across the professions and geographic regions. Consequently, the authors argued the resulting domains "capture at least some of the major ethical and professional issues that arise when patients have genetic concerns" (p. 117). Furthermore, as a majority of anecdotes described by the participants involved at least two of the domains,

McCarthy Veach et al. (2001) suggested genetic counselors should accept the real-world complexity of these issues and “consider multiple, and at times conflicting, ethical principles and professional obligations” (p. 118) while navigating challenging clinical scenarios.

In a follow-up study, Bower, McCarthy Veach, Bartels, and LeRoy (2002) addressed some of the limitations of the previous study by surveying a national sample of genetic counselors. Their questionnaire asked participants to rate all 16 ethical/professional challenge domains for how frequently they encountered each. Participants were also asked to provide a clinical anecdote from their work involving an especially difficult ethical and/or professional challenge and how they might advise a colleague to handle the situation.

Bower et al. (2002) randomly sampled and mailed a paper copy of a cover letter, a survey and a stamped, self-addressed return envelope to a total of 762 full members of the National Society of Genetic Counselors who had seen patients with genetic concerns within the previous two years. A detailed summary of Bower et al.’s (2002) results is beyond the scope of this current review. Particularly related to the current study, however, these authors did find that uncertainty, dealing with patient emotions and diversity issues were among the top five domains rated as occurring frequently by the largest percentages of participants. *Value conflicts* was the second most prevalent challenge illustrated in participants’ anecdotes. This finding is particularly interesting since *value conflicts* was rated as being encountered frequently in one’s daily work by the smallest percentage of participants, although most of the value conflicts described in the anecdotes concerned patient decisions that directly conflicted with the counselors’ own

personal values. The authors speculated that this discrepancy was likely due to the nature of the anecdotes themselves; namely they often depicted more “extreme,” crisis-centered, and somewhat atypical experiences. More studies are needed to explore the reasons value conflicts pose such difficult challenges for genetic counselors, despite their relatively low frequency of occurrence in practice.

Regarding strategies participants recommended to colleagues for managing ethically and/or professionally challenging situations, most prevalent were open discussions with patients, consultation with colleagues, and referring patients to colleagues. Interestingly, the participants rarely recommended disregarding personal beliefs (plausibly interpreted as nondirectiveness). As described earlier, although nondirectiveness has long been a central tenet of the genetic counseling profession, it has received recent challenges regarding its feasibility, and even its appropriateness (Rentmeester, 2001; Suter, 1998; Toth, Nyari & Szabo, 2008; Wachbroit & Wasserman, 1995). Bower et al. (2002) concluded that the strategies noted above (i.e., discussions with patients, consultation with colleagues, and potential referral) are more pro-active solutions, and although nondirectiveness might be possible within any of these three strategies, “it does not appear to be the primary goal” (p. 182).

Of note, Bower et al.’s (2002) findings are limited by participant self-report, the common risk of respondents differing from non-respondents in important but unknown ways, and the likelihood that the previously established list of 16 domains limited participants’ selection of personal anecdotes. In addition, both studies (Bower et al., 2002; McCarthy Veach et al., 2001) asked participants to identify specific ethical and/or professional challenges encountered within their work, but they did not assess the actual

personal beliefs, values and attitudes genetic counselors possess. Thus there is a need for studies that go beyond simply asking what participants think and feel presently but also the types of thoughts, feelings and values they initially bring to their work and how these personal characteristics are shaped over time. Nevertheless, their findings have important implications for the present study. The results suggest genetic counselors do indeed encounter ethical and/or professional challenges somewhat regularly in their clinical practice, even if the frequency of those challenges and their response to them varies. These studies, and those reviewed earlier in the literature review, also suggest the importance of deliberate, self-reflective practice in the training and daily work of genetic counselors, in order to prevent and/or ameliorate negative developmental outcomes (e.g., stagnation, excessive stress, isolation, burnout, compassion fatigue and premature departure from the field) (Zahm, 2010).

**Personal beliefs/values of genetic counselors.** Although a fair amount of the studies reviewed thus far describe the types of challenges genetic counselors experience in their work, empirical understanding of the specific beliefs, values and lessons learned (i.e., potentially unique to those who choose genetic counseling as a career) is limited. In one of the first studies to examine the types of professional development outcomes and lessons learned by genetic counselors while on the job, Runyon and colleagues (Runyon, Zahm, McCarthy Veach, MacFarlane & LeRoy, 2007) surveyed 185 genetic counselors. Their respondents identified the most important thing they had learned about themselves since initiating clinical practice and offered advice for genetic counseling students just starting their careers. Utilizing an interpretive content-analysis approach, the researchers

extracted a combination of interpersonal, intrapersonal and professional lessons as themes emerging from participant responses.

Within the intrapersonal lessons specifically, Runyon et al.'s (2007) participants discussed developing strong insights over time regarding their own self-efficacy, the synergistic relationship between their personal and professional experiences, and the need to let go of control (e.g., by managing one's values/biases/opinions, accepting others' viewpoints, and accepting that some matters are uncontrollable). Similar to Zahm (2010), these authors concluded counselor self-awareness, self-reflection and learning from others are "necessary catalysts" (p. 382) for these insights to transfer to actual outcomes.

Within the interpersonal lessons theme, participants spoke of having especially meaningful relationships with their patients, often resulting in increased empathy and making a significant difference in patients' lives. They also spoke of the powerful experience of uncertainty within the scope of their work, stemming from "gray areas" (Runyon et al., 2007, p. 378) with patients and ambiguous outcomes. While a few participants described this ambiguity as particularly difficult and stressful, most participants eventually came to realize that it is acceptable to not have an answer to everything.

Within the professional lessons theme, many participants provided detailed responses about desirable aspects of their jobs that they have experienced over time, including varied tasks such as clinical work, teaching, mentoring, problem solving and research. A few participants also spoke of the stress inherently involved in dealing with challenging clinical scenarios, unmet expectations and (sometimes) increased

disillusionment within one's job position. Nevertheless, almost half of the participants also spoke openly about their steady commitment to lifelong learning that has been satisfied (if not strengthened) by their work as genetic counselors.

The results of the Runyon et al. (2007) study align strongly with the aims of the current study. While those authors asked participants what they have learned on the job since entering the profession, the current study asked additional questions of how genetic counselors tended to define an overall sense of personal *meaning* prior to entering the field and what types of lifetime sources (i.e., before and during one's clinical practice) influence their definition of *meaning* over time. Furthermore, Runyon et al. (2007) suggested genetic counselors in training be provided more opportunities to engage in more thorough self-reflective practices and make connections between their personal lives and professional lives, which is exactly what the current study aimed to do.

Pirzadeh and colleagues (Pirzadeh, McCarthy Veach, Bartels, Kao & LeRoy, 2007) also conducted the first published study that attempted to generate a deeper understanding of genetic counselors' personal values, by use of a standardized measure. They administered the original version of the *Schwartz Universal Values Questionnaire* (SUVQ; Schwartz, 1992), to 292 genetic counselors. The SUVQ is comprised of 56 specific value words and phrases along with explanatory definitions (organized into 11 different *value types*). Participants are instructed to rate the values most important and least important to them in their own lives. The researchers also included demographic items, as well as an open-ended question regarding how influential the participants thought their personal values are within ethically challenging situations in their practice.

The researchers found a few significant differences in ratings due to gender (e.g., males tended to value power and instrumentality in relationships more so than females who tended to value expressiveness and nurturance), religious practice (e.g., those identifying as religious tended to score higher on values of tradition and spirituality and lower on stimulation and hedonism), and parental status (e.g., those with children tended to score lower on values of achievement and stimulation). Nevertheless, the researchers also found that genetic counselors as a whole tended to identify benevolence, self-direction, achievement and universalism as their most highly important values, with stimulation, tradition and power as comparatively less important. These findings were nearly identical to findings in studies of mental health counselors (Kelly, 1995), family physicians (Eliason & Schubot, 1995), and physical therapists (Nosse & Sagiv, 2005), with the exception of achievement.

Overall, Pirzadeh et al. (2007) suggested benevolence and universalism represent a self-transcendence (concern for others) value type, and self-direction potentially reflects an openness to change. They further concluded the apparent preference for self-transcendent values over self-enhancement values seems to “support the basic tenets and goals of genetic counseling (e.g., respect for autonomy, interpersonal concern, empowerment of the individual, and a valuing of the practitioner-patient relationship)” (p. 770). The high ranking of the self-enhancement value type of achievement was somewhat surprising, but the authors suggested it might be due to genetic counselors feeling a desire (and/or need) to be experts when providing specific genetic information to patients. A desire for intellectual stimulation, in addition to a strong desire to help others, has also been documented in the findings of Lega, McCarthy Veach, Ward and

LeRoy (2005) who surveyed genetic counseling graduate students about their specific motivations for entering the field.

Pirzadeh and colleagues (2007) identified the limitations to this study as including a low response rate (22%), restriction of range for variables such as gender and ethnicity (thus limiting the scope of potential statistical analyses), and the common concern that respondents may potentially differ from non-respondents in important but unknown ways. Nevertheless, this study is an important contribution to the literature, and is especially relevant to the current study, as the findings suggest a typical values profile for practicing genetic counselors. The researchers emphasized that when genetic counselors provide clinical service to patients, “who they are may play as important a role as what they know” (p. 763). They also argued that clinicians’ personal values may indeed influence their presentation of facts and decision options to patients, as well as whether they invite patients to consider their own moral consequences related to their decisions. Pirzadeh et al.’s (2007) findings may also further challenge the once held idea that genetic counseling is a value-neutral profession. In fact, these authors strongly recommended training curricula and clinical (formal and informal) supervision that specifically invite genetic counselors to engage in self-reflective practice for the purpose of increased individual awareness and management of personal values and their effects on clinical practice.

**Religiosity and spirituality in genetic counselors.** Research has shown the constructs of religiosity and spirituality play important roles for many people, especially when faced with stressful life experiences (Bjork & Thurman, 2007; Pargament, 1997; Zinnbauer et al., 1997). Within the context of genetic counseling specifically, it is

common for patients to consider these same constructs while making decisions around genetic testing, pursuit of treatment, and pre-term abortion (Schwartz et al., 2000; White, 2006). In contrast, Pirzadeh and colleagues (2007) found the value of spirituality, broadly defined as “discovering *meaning* in life and inner harmony for self through various methods” (Schwartz, 1992, as cited in Pirzadeh et al., 2007, p. 768) to be the fourth lowest ranked genetic counselor value. This finding is noteworthy, especially considering the majority of genetic counselors in another study self-identified as being moderately to highly spiritual (Cragun, Wotanski, Myers & Cragun, 2009). Despite these equivocal findings it is important to consider the roles these constructs play for genetic counselors in their professional and personal lives.

Cragun and colleagues (2009) found that of 680 sampled genetic counselors, the overall percentage who identified with a religious affiliation was very similar to that of the general U.S. population (i.e., around 80%), but they were significantly less likely to identify with conservative Christian religions, believe in god, attend religious services, pray, and believe in an afterlife. When the construct of religiosity is defined more broadly as including some of these latter variables, rather than religious affiliation alone, genetic counselors report lower levels of religiosity compared to the general US population. Cragun et al. speculated their findings reflect a potential tolerance for various worldviews and patient autonomy during genetic counseling sessions. They further hypothesized that because years of genetic counseling experience was not significantly related to overall levels of religiosity, genetic counselors’ beliefs and practices may already exist when they decide to enter the profession, rather than being affected by some aspect of the profession that would make them less religious over time.

It might also be hypothesized, however, that some aspect of graduate preparation affects genetic counseling students' religiosity, an effect that persists once graduated; this hypothesis should be studied in future research. Of note, Cragun et al.'s findings are based solely on genetic counseling participants' responses to a 10-point investigator-developed scale, with 1 being "not at all spiritual" and 10 being "very spiritual." Further research is warranted to explore the specific *meaning* of spirituality for genetic counselors and how their beliefs might intersect with their practice and with their patients' *meaning* of spirituality over time. Longitudinal research also is needed to determine the stability of genetic counselors' religiosity. Clearly, further research is needed to identify the values, beliefs and *meaning*-making of individuals who self-select into the field of genetic counseling.

**Individual qualitative accounts.** While most of the studies reviewed thus far have attempted to identify genetic counselors' personal beliefs and values through the use of survey and focus group data, several accounts based on individual interviews and/or case studies also contribute to a broader understanding of these questions. These include accounts regarding genetic counselors' personal and internal lives (e.g., Abrams & Kessler, 2002; Kessler, 1992; McCarthy Veach, Bartels & LeRoy, 2002; Resta, 2002), and through defining moments as spouses (Gordon, 2012), mothers (Anonymous, 2008; Bellcross, 2012; Clark, 2010; Menezes, Hodgson, Sahhar, Aitken, & Metcalfe, 2010), daughters (McCarthy Veach, 2006), program directors (Campion, 2012), graduate students (Bradley, 2012; Redlinger-Grosse, 2012), researchers (Bordutha, 2012), patients (Anonymous, 2012; Glessner, 2012; Jonas, 2012), and clinicians (Chin, 2012; Curnow, 2012; Flynn, 2012; Hopkins, 2012; Infante, 2012; Knutzen, 2012).

In “The Inner World of the Genetic Counselor,” Abrams and Kessler (2002) provide a set of emotionally-poignant and engaging hypothetical vignettes to provide a realistic and rich description of the intersections between genetic counselors’ personal lives and professional lives; and to illustrate how these intersections inform a developmental path throughout one’s career. Some of the stories detail challenging emotions (e.g., fear, regret, anxiety) around delivering bad news to a patient, while others describe some of the private judgment clinicians experience when they do not feel their patients are making the most informed or appropriate decision. Several others describe the common experience of feeling increasingly content over time when one realizes it is not only acceptable but expected that not all patients can be helped in a way that feels as significant as the genetic counselor had hoped. The authors encourage their readers to engage in critical self-reflection as they read through the stories and “invite them to enter the scene, to identify with any of the ‘players’ and to experience the thoughts or feelings evoked in themselves” (p. 7).

Abrams and Kessler (2002) also argue that revealing the “inner world” (p. 5) of genetic counselors is necessary in order to fully understand their total experience. In this sense, to ignore the strengths, weaknesses, beliefs, values and sensitivities genetic counselors themselves bring to a professional relationship with patients would be to leave out at least half of the essence of the genetic counseling experience. They describe genetic counseling as addressing “the nitty-gritty of human dreams and wishes and hopes and the quotidian existence of joy and pain and – for better or worse – it’s based on a relationship between real thinking and feeling people” (p. 16). Similarly, in order to appropriately manage the countertransference often experienced in genetic counseling

(Kessler, 1992), some authors suggest genetic counselors must “figure out why [certain] patients are sticking like bubblegum to the bottom of [their psyches]” (Resta, 2002, p. 20). Consequently, developing a deep understanding of one’s own personal sense of *meaning*, as well as a willingness to explore its potential influence on patients’ worldviews, seems imperative to assuring high quality and effective genetic counseling services.

Abrams and Kessler (2002) emphasize that, although fictional, these vignettes illustrate how genetic counselors’ internal psychological worlds do not always follow as linear of a path as the science and practice of genetic counseling. They warn that attempting to apply linear thinking and practice while engaging with the intense, abstract and ever-changing emotional experiences of patients often results in undesirable counseling outcomes, dissatisfied patients and frustrated clinicians. Similarly, Abrams and Kessler (2002) challenge a historical tendency to conceptualize the profession of genetic counseling “at a distance, as if to touch the flesh and blood of its reality would somehow, in its subjectivity, contaminate the professional’s vision” (p. 16). Instead, they encourage genetic counselors to view their work as a “process of communication ... [and as] ... an interaction between human beings” (p. 16) rather than a formulaic sequence; they emphasize the importance of self-awareness, humility and strong relational skills. Subsequently, a primary purpose of the present investigation is to elicit true accounts from practicing genetic counselors about how they navigate their own complex internal worlds of thoughts, feelings and values while working with patients who both challenge and reaffirm their sense of *meaning*.

In order to further examine the nature and implications of genetic counselors' inner lives, McCarthy Veach, Bartels and LeRoy (2002, 2012) published two series of "Defining Moments" essays, ten years apart, asking genetic counselors to provide a narrative to the most noteworthy and/or meaningful catalysts for their personal and professional development since entering the profession. The genetic counselor authors ranged widely in age, experience level, and specialty area. McCarthy Veach et al. (2012) describe this project as based in their strong, mutual assumption that clinicians grow stronger both professionally and personally when they take the opportunity to self-reflect on their own direct experiences, as well as reflect upon (and relate to) their colleagues' meaningful experiences. Furthermore, they argue that the power in clinicians' defining moments comes from a "readiness to learn from their experience, ability to engage in honest and often painful self-reflection, and their efforts to generalize their learning to their 'personal' and 'professional' selves" (p. 163).

The "Defining Moments" series helps illuminate a number of lessons regarding the importance of increased self-reflection and insight into the person of the genetic counselor. For example, learning what it means to be helpful (e.g., the importance of listening, taking risks within sessions, supporting patient autonomy, and tolerating patient affect) often needs to come directly from patients. For example, Curnow (2012) offers, "I am privileged to witness the resilience of others, draw strength and conviction from their presence, to feel overwhelmed, but also [feel] respected and valued when I am thanked by those who, it seems, have so little for which to be thankful" (p. 184). Knutzen (2012) describes that her work with patients in incredibly challenging situations has helped her develop a strong appreciation for the experiences of hope and perseverance (e.g., "it is

not our job to extinguish . . . hope, but rather to dance the fine line between igniting the flames of unrealistic hope and smothering the flames of what little hope may remain” (p. 206)). Similarly, Chin (2012) describes how her patients taught her to eventually realize that “not everything in genetics is genetic” (p. 181).

The “Defining Moments” authors also emphasize the critical importance of honoring their own personal life events and working to understand their potential and actual influences on their work with patients. Anonymous (2012) states, “just like the families we care for, genetic counselors each have a story that must be acknowledged and honored” (p. 168), and that her own personal illness has taught her she “cannot separate [herself] from her counselor-self because ‘we’ are far stronger together than we could be apart” (p. 168). Through having navigated challenging developmental issues of her son, Bellcross (2012) also emphasizes that “as genetic counselors, we must remember that [the phrase] ‘it could have been worse’ is meaningless for those who are experiencing the loss of their hoped-for child, no matter what the circumstances” (p. 172).

And finally, the “Defining Moments” authors acknowledge the importance of professional milestones of graduate school education, licensing/credentialing, and professional membership in providing meaningful experiences for genetic counselors. In this regard, Bradley (2012) reminds readers about the necessity of realizing that “failing is hard, but it’s not even close to being the worst thing in the world” (p. 176), and that even in the face of academic and/or professional struggles, “[she] not only cultivated confidence in [her] capabilities as a genetic counselor, but [she] also developed deep pride in [her] work” (p. 176). Amidst new professional endeavors, Campion (2012) learned that “perseverance is much more important than perfection” (p. 180). In addition,

there seems to be no set threshold or end-point for competency within the profession of genetic counseling, and Flynn (2012) nicely summarizes her own professional development over time as a process of ongoing commitment to self-reflection and professional growth: “I fulfill my role as a genetic counselor while developing into a better one” (p. 186).

Certainly, there are limits to self-report essays in that they are not easily generalizable to the broader population and they are often subject to socially desirable, overly positive descriptions (i.e., shaped to satisfy a researcher’s agenda [Heppner, Kivlighan & Wampold, 1999])). Of note, however, no obvious concerns regarding the latter limitation were evident within the “Defining Moments” series. In fact, every account spoke strongly to the self-doubt and even self-berating experiences that arise within the challenging work of genetic counseling. In other words, the authors’ levels of honesty and vulnerability seem to be a particular strength of this series of articles.

In describing the “Defining Moments” collectively, McCarthy Veach et al. (2012) argue that self-reflection regarding important catalysts in one’s professional development across the career life-span helps further strengthen genetic counselors’ personal qualities and counseling skills of “empathy, authenticity, honesty, self-awareness, resiliency, compassion, connection, courage, and commitment” (p. 166). Their arguments are similar to Zahm’s (2009) emphasis on the importance of self-reflecting on poignant turning points within one’s professional career as “giving voice to experiences that might otherwise go untold ... [so as] to promote the development of genetic counselors and the collective profession [as a whole]” (p. 29). In essence, giving such a *voice* to such important stories through active self-reflection is one of the primary intentions of the

current investigation.

### **Synthesis**

As mentioned previously, no research to date has explicitly examined how genetic counselors develop, experience or express a sense of *meaning* as part of their work. In order to initiate a foundational understanding of how this construct might be experienced, this review first considered a few historical underpinnings of existential thought as they relate to *meaning* experienced by helping professionals. Next, this investigator examined a few specific research agendas (within and beyond the field of genetic counseling) to draw parallels between established professional developmental tasks and one's overall experience of *meaning* (e.g., self-reflective practice and integration of self). The last section of the review concerned how practitioners might define, approach and experience issues of *meaning* within the contexts of daily clinical practice, professional/ethical dilemmas, challenging patient scenarios and defining moments throughout their careers (again sometimes relying on loose parallels, as the specific construct of *meaning* is rarely mentioned in this literature).

### **Purpose of the Present Study**

The purpose of the present study was to explicitly examine the construct of *meaning* with genetic counselors by asking them to consider their general views on *meaning*, their perspectives on how their views have been influenced and/or shaped over time, and the types of clinical contexts that both challenge and reaffirm their personal sense of *meaning*. Also, although a number of the reviewed studies in this chapter loosely imply experiences of personal *meaning*, most are based on questions regarding one's current perspective, or on hindsight. One primary intention of the current study was to

garner a more comprehensive and holistic perspective regarding how genetic counselors develop, experience and express the construct of *meaning* throughout their work (and lives). Strengthening the profession's holistic understanding of *meaning* within (and beyond) counselors' clinical practice will help to inform specific training, supervision, and practice guidelines within genetic counseling.

## Chapter 3

### Methodology

#### Sample

Upon receipt of approval from the University of Minnesota Institutional Review Board, an electronic invitation to participate in an anonymous online survey was sent to members of the National Society of Genetic Counselors (NSGC) email listserv (~ $N = 1400$  members). The electronic invitation (see Appendix A) described this research as a “study exploring larger issues of *meaning*, especially as they relate to the interface between your personal life and professional experiences as a genetic counselor.” The invitation was sent twice (two weeks apart) in April 2011. Each invitation to participate contained a link to access the survey. Consent was implied by participants voluntarily accessing the survey via the link and providing their contact information if interested in completing a follow-up telephone interview. A total of 298 participants completed the online survey and 92 of those participants were willing to be contacted for an interview. Participant demographics are summarized in Table 1 and described in Chapter 4.

Although qualitative researchers typically conduct no more than 12-15 interviews within their studies, due to the strong likelihood of reaching thematic saturation (Hill, 2012), it was determined by this investigator and his research advisors that more interviews would be conducted for the present study. This decision was made for three primary reasons. First, it was suspected that the abstract nature of the interview questions would make it less likely that highly differentiated and prevalent domains could be extracted within a small sample (Morse, 2000). Second, more interviews were conducted in order to assure that a number of individuals from each of ten major genetic counseling sub-specialties were represented. Third, there was a seemingly strong participant interest

(i.e., almost 100 individuals indicated they were interested in being contacted for an interview), and the primary investigator wanted to maximize the opportunity for participants to have their voices heard in the research results.

A purposive process was used to select participants for interviews. Individuals reporting certain low-incidence demographic characteristics were first over-selected (i.e., male gender, ethnic minorities, greater than 20 years of experience as a genetic counselor, and a few particular religious identifications such as Buddhist, Greek Orthodox, and Friends/Quaker). Additional participants were selected based on the remaining characteristics assessed in the survey; the goal was to obtain interviewees that approximated the proportions of those characteristics represented in the original survey sample. A total of 70 interviewees were selected with this method, and 68 of these individuals completed follow-up interviews. Two individuals withdrew from the study after several failed attempts to identify a suitable date and time for the interview.

A similar design process was used to select 25 participants from the interview sample to include in the final qualitative data analysis. Again, the same low-incidence characteristics as described above were over-selected. For example, all three males who volunteered for the follow-up interview and all four counselors who identified as an ethnic minority were included in the data analysis. Next this investigator selected individuals whose remaining characteristics were representative of the interview sample. He employed a third criterion for the latter step – choosing individuals who were not only representative but also whose interviews were particularly engaging and/or unique. Finally, this investigator listened to the remaining interviews and read through his

interview notes in order to assure that no other prominent themes were missed in the non-analyzed data.

### **Instrumentation**

**Online survey.** The online survey (presented in Appendix B) consisted of a cover page describing its content and research objectives; 12 questions requesting demographic information (age, gender, ethnic/racial background, relationship status, parental status, religious/spiritual affiliation, years of genetic counseling experience, specialty area, primary employment setting, geographic region of practice, whether or not the respondent currently sees patients, and number of patients seen weekly on average); and the *Meaning in Life Questionnaire (MLQ)*; Steger, Frazier, Oishi & Kaler, 2006). A description of the *MLQ* and data from the *MLQ* are reported elsewhere (Wells, 2012). They are not part of the present investigation. A final item invited respondents to provide their name and contact information if they were willing to be contacted for further discussion of their responses. A draft of the survey was piloted with two advanced genetic counseling students. Minor revisions to the wording for a few demographic questions were made based on their feedback in order to both clarify content and improve readability.

**Interview questions.** Nine open-ended questions and related question-prompts were developed for use in the interviews (See Appendix C). They were derived from a review of genetic counseling literature and the primary investigator's discussion of clinical and research experiences with two of his committee members (i.e., a licensed psychologist experienced in genetic counseling research and a genetic counseling program training director). The questions variously invite comments about how the

participants define a sense of *meaning* for themselves, their lifetime sources of influence on those definitions, how they experience *meaning* within their genetic counseling practice (in both reaffirming and challenging clinical scenarios), how those definitions have changed over time, and why they chose to participate in the study. The interview protocol was piloted with two advanced genetic counseling students in order to anticipate potential participant responses, reactions to questions, and fatigue during the interview. Minor revisions were also made to the interview questions to strengthen the clarity of the questions based on the pilot participants' feedback.

### **Procedure**

**Interviews.** Genetic counselors selected to participate in the interview portion of the study were contacted through email by the primary investigator (see Appendix D) in order to schedule a 30-45 minute audio-recorded phone call for completing the interview. Those who did not respond within one week of the first email invitation received the same invitation a second time. No further attempts were made if selected participants did not respond to either of these invitations. Upon securing a date and time for an interview through email correspondence, this investigator emailed the selected participants a copy of the formal consent form for their records (see Appendix E) and the interview questions (see Appendix C) for their review prior to participating in the interview. Not sending the interview questions ahead of time was considered, but there was a consensus among the pilot participants and members of the research team that participants might feel surprised and/or confused with the broad and abstract nature of the questions if they did not review them in advance of the interview.

All interviews were conducted between April, 2011 and August, 2011. During the first few minutes of each telephone interview, the primary investigator reminded the interviewee about her or his right to withdraw from participation in the study at any time. He then secured a follow-up, verbal consent to proceed with audio-recording the interview. A few demographic items from the online survey related to work experiences were also reviewed with each participant as a means to assure their accuracy (specifically, to account for the time period between the survey and the interview), as well as to begin setting a conversational tone and casual rapport for the interview itself. Finally, this investigator briefly reviewed the purpose of the study and read the following prompt verbatim to each participant:

*The purpose of this study is to explore issues and questions of meaning experienced by genetic counselors and to examine how they personally manage these issues and questions. Everyone has ways of making sense of things that happen to them and others. I am interested in how you do this for yourself, especially as it relates to your experiences as a genetic counselor over time. For this study, participants are encouraged to think about what makes their lives feel important to them, which may or may not include things such as relationships, work, leisure and values. In addition, participants are encouraged to consider the term “meaning” within the broad scope of any religious, spiritual, existential, philosophical, or ecological realms to which they may relate.*

The primary investigator, a Caucasian, male doctoral candidate in counseling psychology, then conducted a semi-structured interview with each participant. A semi-structured approach ensures that questions are asked in the same sequence and allows for

prompts and follow-up/clarifying questions, as appropriate (Patton, 2002). Following completion of the interviews, the primary investigator transcribed the interview content verbatim, with the help of two Master's level students in counseling psychology. All identifying information was removed from the transcripts.

### **Data Analysis**

Analysis of the interview involved a phenomenological approach, intended to provide a complete description of the phenomenon (McLeod, 2001) being explored. Researchers utilize this approach in an attempt to describe the phenomenon as close to reality as possible (Colaizzi, 1978) by identifying and setting aside their own personal experiences and biases prior to collecting and coding the interview responses.

**Analysis team preparation.** The primary analysis team for this project consisted of the primary investigator and two graduate student research assistants. Both research assistants were Master's level students in counseling psychology from two different academic institutions (one female and one male; both Caucasian). Only one of the assistants had any prior exposure to the field of genetic counseling through a concurrent basic counseling skills course that included both counseling psychology masters students and genetic counseling masters students. This investigator provided team members with a general description of the genetic counseling field and a copy of the interview questions in order to both help familiarize them with the scope of the project and to facilitate bracketing of their potential expectations/biases during the analysis phase. Also, as neither masters student had previous experience with Consensual Qualitative Research (CQR) they were asked to review two primary publications on the analysis method (i.e., Hill, Thompson, & Nutt-Williams 1997; Hill et al., 2005).

**Bias bracketing.** The bias bracketing documents are presented in Appendix F and summarized here. In general, participants were predicted to be thoughtful, self-reflective, open and articulate, based on their motivation to self-select into the interview as well as their shared graduate-level educational backgrounds. Nevertheless, it was thought that the participants might also struggle with the abstract nature of the questions and would benefit either from receiving the interview questions ahead of time or at least from consistent prompts from the interviewer to be specific in their responses. The team also predicted that participants would present as fairly open-minded and others-focused due to their decisions to pursue a career within a helping profession such as genetic counseling.

The analysis team also discussed what some of their expectations were regarding participant responses to the specific interview questions. Members of the team predicted that participants would define their general sense of *meaning* with broad examples of satisfying interpersonal relationships, helping others, and other faith-based ideals. Similarly, the team expected that these same realms would likely have served as important sources and influences on the participants' sense of *meaning* throughout their lives. One team member also suggested that there might be a theme related to work/life balance issues due to the busy and intense nature of the genetic counseling profession.

For the questions specific to the connections between *meaning* and genetic counseling practice, the team predicted that the participants would provide examples of when they have been able to help their patients, regardless of what form that help has taken. Examples of this help were suspected to be supporting, providing information and empowering their patients to make decisions for themselves. The team members expected participants to say that their sense of *meaning* is challenged when they feel they are not

directly helping their clients in these sorts of ways. The team also unanimously expected that participants would provide clinical anecdotes, for when their sense of *meaning* has been challenged within their work, specific to value conflicts with patients. However, one member expected this to be less the case for counselors who had been practicing for a longer period of time. Overall, the team also expected to hear from participants about how their sense of *meaning* has become less contingent on direct patient outcomes over time and maybe more on the process of connecting with their patients through their stories, offering support and developing empathy.

**Data analysis methods.** Basic descriptive statistics were calculated for all major demographic items from the online survey. As most items were categorical in nature, and a few (i.e., ethnic/racial background, religious/spiritual affiliation, specialty area) were constructed with “check all that apply” response options, only frequencies were calculated and presented for these items. These data are presented in Tables 1 and 2 and summarized in Chapter 4.

Using CQR methods (Hill, 2012; Hill et al., 1997; Hill et al., 2005) the team classified interview responses in an inductive manner. Typically, the CQR method involves a four-step protocol. First, the team creates major topic areas (also known as domains) in which they group conceptually similar interviewee responses. Second, potential categories (more specific topics within domains) are considered for further refinement, and definitions are provided to summarize the core ideas from these domains and categories. Third, the interviews are cross-analyzed as a means to tabulate specific frequency of categories across cases (participants). Within this step, titles of *General*, *Typical*, *Variant*, and *Rare* are assigned as a means to compare the relative frequency of

each category. *General* is used when all or all but one or two participants are represented. *Typical* is used when more than half of the participants are represented. *Variant* is used when less than half, but more than one or two participants, are represented. *Rare* is used when only one or two participants are represented. Finally, a member of the research team not involved in the coding audits the data to assess whether the classifications appear accurate and/or appropriate.

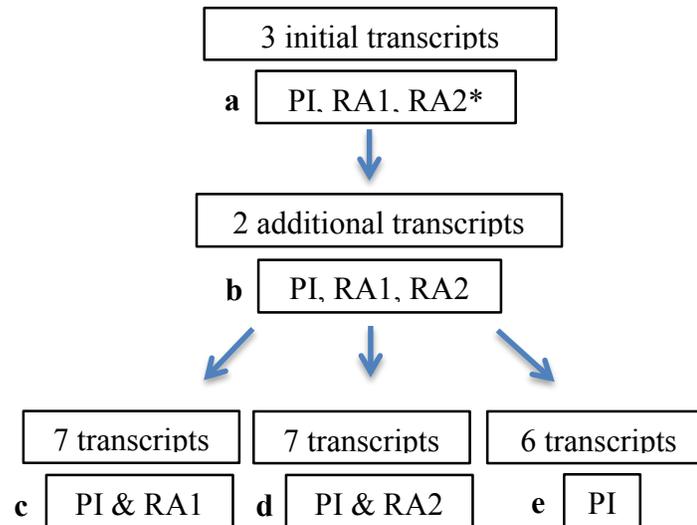
It should be noted that the research team decided to not utilize the third step as described above in the current study. Due to the broad scope and abstract nature of the interview, questions were scripted specifically as a way to elicit unique responses among participants about how they define and experience *meaning* within their lives. It was expected that participants might respond to such personal questions with potentially more differences than similarities. Consequently, within the total data set, none of the resulting categories were identified as *General* (i.e., all or all but one or two participants being represented), and only seven of the categories were even identified as *Typical* (i.e., more than half of the participants being represented).

The specific analysis sequence utilized by the data analysis team is presented in Figure 1. All three members of the analysis team first independently read through three interview transcripts in order to get a sense of the interview's scope and identify what they regarded as the most salient themes within participant responses. The team met on three separate occasions to discuss these themes until consensus was reached regarding the most significant aspects of each response. Throughout this process, the analysis team made different attempts at classifying data into initial domains and categories based strictly on the interview questions themselves, as well as in a strict inductive manner

from the responses themselves. These considerations (along with two of these transcripts) were sent to the data auditor, a licensed psychologist well-versed in CQR methodology and genetic counseling research, for the purpose of initial auditing and re-framing the analysis approach as necessary. The research team met again on four more occasions to discuss each other's suggestions for two additional transcripts, until a consensus was reached regarding the initial domains and categories as well as their respective titles and definitions.

The preliminary domains and categories identified in these first five transcripts were then used as a guide for the remaining 20 transcripts and CQR analysis. Each of the assistants independently coded seven additional transcripts. This investigator met three times with each of the assistants in succession to compare his own classifications on these same transcripts, discuss disagreements and come to consensus. Whenever a seemingly important aspect of a participant response did not fit easily within any of the established domains or categories, either the definition of the domain/category was adjusted accordingly, or a new domain/category was created. The primary investigator then reviewed all 19 transcripts that had been coded up to that point in order to reclassify responses into the new domains and/or categories as appropriate. And finally, the primary investigator independently coded the six remaining transcripts, using the domain list that had been constructed and refined with the research assistants. In total, 25 interview transcripts were coded with this method and the list of categories and domains was revised through consensus on thirteen different occasions. Each master's student team member reviewed 19 transcripts, and the primary investigator reviewed every transcript.

The data auditor again reviewed the final coding, and the analysis team met once again for final consensus following that review.



*Figure 1.* Analysis sequence utilized by the Consensual Qualitative Research (CQR) data analysis team. Consensus regarding thematic domains and categories was reached by the team members identified at each stage (a-e), and the principle investigator reviewed all previous transcripts to reclassify as necessary. \*PI = Principle investigator, RA1 = Research assistant one, RA2 = Research assistant two.

## Chapter 4

### Results

#### Participants

A total of 298 genetic counselors completed the initial survey. Based on the estimated membership of the National Society of Genetic Counselors (NSGC) email listserv ( $\sim N = 1400$ ), the initial response rate was 21%. Of those who completed the initial survey, 31% ( $n = 92$ ) consented to participate in follow-up interviews.

Demographic characteristics for individuals who completed the initial anonymous survey, along with those chosen for interviews and those not chosen for interviews, are presented in Table 1. Both personal variables (e.g., gender, ethnicity, age, etc.) as well as work-related variables (e.g., years of genetic counseling work experience, specialty area, primary work setting and geographic region) are represented. Of note, all variable percentages for the total sample appear comparable to the percentages for the interviewees and non-interviewees. Statistical analyses could not be conducted between these groups, however, due to the over-selection of certain low-incidence variables (e.g., male gender, non-Caucasian ethnic identification) intended to assure representation in the interviews, thereby violating assumptions of independence required for a chi-square test of independence.

The total sample was largely Caucasian (93%) and female (97%), both of which appear consistent with previous estimates of the population of genetic counselors (NSGC Professional Status Survey, 2012). Most participants were married or in a marriage-like relationship (79%), did not have children (56%), and were between the ages of 20 and 40 (73%). As for religious and/or spiritual affiliations (of which participants could check all

Table 1

*Demographics of Interviewees (n = 68), Non-Interviewees (n = 230) and Total Sample (N = 298)*

Variable	Interviewees		Non-Interviewees		Total Sample	
	<i>n</i>	%	<i>n</i>	%	<i>N</i>	%
Gender						
Female	65	95.6	224	97.4	289	97.0
Male	3	4.4	6	2.6	9	3.0
Ethnicity						
Caucasian	63	92.6	213	92.6	276	92.6
Non-Caucasian	5	7.4	17	7.4	22	7.4
Age (years)						
20-30	18	26.5	89	38.7	107	35.9
31-40	32	47.1	79	34.3	111	37.2
41-50	13	19.1	38	16.5	51	17.1
51-60	5	7.4	19	8.3	24	8.1
61+	0	0.0	5	2.2	5	1.7
Relationship status						
In a marriage like rel.	49	72.1	131	57.0	180	60.4
Married	7	10.3	48	20.9	55	18.5
Single/never been married	6	8.8	44	19.1	50	16.8
Separated or divorced	3	4.4	3	1.3	6	2.0
Parental status						
No children	35	51.5	133	57.8	168	56.4
Children	33	48.5	97	42.2	130	43.6
Religious/Spiritual Affiliation <sup>a</sup>						
Agnostic	15	22.1	33	14.3	48	16.1
Roman Catholic	8	11.8	49	21.3	57	19.1
Christian (Disc. of Christ)	8	11.8	16	7.0	24	8.1
None	6	8.8	37	16.1	43	14.4
United Methodist	6	8.8	17	7.4	23	7.7
Atheist	6	8.8	16	7.0	22	7.4
Baptist	5	7.4	10	4.3	15	5.0
Lutheran	4	5.9	12	5.2	16	5.4
Episcopalian	4	5.9	3	1.3	7	2.3
Jewish	3	4.4	25	10.9	28	9.4
Presbyterian	2	2.9	13	5.7	15	5.0
Unitarian	2	2.9	8	3.5	10	3.4
Greek Orthodox	1	1.5	0	0.0	1	0.3
Friends (Quaker)	1	1.5	1	0.4	2	0.7
Buddhist	1	1.5	5	2.2	6	2.0
Islamic	0	0.0	1	0.4	1	0.3
Hindu	0	0.0	3	1.3	3	1.0
Other	9	13.2	14	6.1	23	7.7

*Note.* <sup>a</sup> Respondents could check all that apply; n's vary as not all participants answered every item.

Table 1 (Continued)

*Demographics of Interviewees (n = 68), Non-Interviewees (n = 230) and Total Sample (N = 298)  
(Continued)*

Variable	Interviewees		Non-Interviewees		Total Sample	
	<i>n</i>	%	<i>n</i>	%	<i>N</i>	%
Years of Gen Coun Exp						
Novice (0-5)	27	39.7	105	45.7	132	44.3
Experienced (6-14)	27	39.7	74	32.2	101	33.9
Seasoned (15+)	14	20.6	50	21.7	64	21.5
Geographic region						
I (Northeast)	7	10.3	14	6.1	21	7.0
II (East)	15	22.1	52	22.6	67	22.5
III (South/southeast)	9	13.2	32	13.9	41	13.8
IV (Midwest)	18	26.5	69	30.0	87	29.2
V (Mountain)	9	13.2	24	10.4	33	11.1
VI (West/northwest)	10	14.7	33	14.3	43	14.4
Primary work setting						
University	29	42.6	91	39.6	120	40.3
Private hospital	16	23.5	71	30.9	87	29.2
Diagnostic lab	8	11.8	14	6.1	22	7.4
Group practice	1	1.5	9	3.9	10	3.4
Government office	1	1.5	7	3.0	8	2.7
HMO	1	1.5	4	1.7	5	1.7
Individual practice	0	0.0	6	2.6	6	2.0
Other	12	17.6	26	11.3	38	12.8
Specialty area <sup>a</sup>						
Prenatal	31	45.6	94	40.9	125	41.9
Cancer	26	38.2	82	35.7	108	36.2
Pediatrics	21	30.9	66	28.7	87	29.2
Molecular	9	13.2	12	5.2	21	7.0
Specialty disease	9	13.2	10	4.3	19	6.4
Neurogenetics	8	11.8	10	4.3	18	6.0
Teratogen	4	5.9	7	3.0	11	3.7
Infertility	3	4.4	6	2.6	9	3.0
Public health	0	0.0	10	4.3	10	3.4
Psychiatric	0	0.0	3	1.3	3	1.0
Other	13	19.1	36	15.7	49	16.4

*Note.* <sup>a</sup> Respondents could check all that apply; n's vary as not all participants answered every item.

that apply), the most prevalent identifications were Roman Catholic (19%), agnostic (16%), and none (14%), with all other endorsed options less than 10%.

Regarding work-related demographics, participants tended to be novices with fewer than five years of genetic counseling experience (44%), work in the Midwest (30%), practice in university hospital settings (40%), and specialize in prenatal (42%), cancer (37%) or pediatric genetic counseling (29%). Demographic statistics for the interviewees included in the data analysis, along with those who were not included in the data analysis, are presented in Table 2. Those individuals included in the data analysis were largely Caucasian (84%) and female (88%). The majority was married or in a marriage like relationship (80%), did not have children (56%), and was between the ages of 20 and 40 years (77%). As for religious and/or spiritual affiliations, the most prevalent identifications were Roman Catholic (16%), agnostic (16%), Christian (12%), and none (12%), with all other provided options fewer than 10%. Regarding work-related demographics, the largest percentages of participants were either novice (40%) or experienced (40%), worked in the East (28%) or Midwest (28%), practiced in university hospital settings (40%), and specialized in prenatal genetic counseling (44%), pediatric (36%), or cancer genetic counseling (32%). Again, it should be noted that the demographic frequencies for interviewees included in the data analysis and those not included appear to be generally comparable to each other (as well as to the total sample), but statistical differences between these groups could not be calculated between these groups due to over-selection of certain variables violating the required assumptions of independence inherent to those tests.

### **Interview Characteristics and Clinical Impressions of Interviewees**

The interviews ranged in length from 15 to 50 minutes (median = 34.5 minutes). Several interviews were briefly interrupted with technical difficulties such as a dropped

Table 2  
*Demographics of Interviewees Included in Qualitative Data Analysis (n = 25) and Those not Included in the Qualitative Analysis (n = 43)*

Variable	Data Analyzed		Data Not-Analyzed	
	n	%	n	%
Gender				
Female	22	88.0	43	100.0
Male	3	12.0	0	0
Ethnicity				
Caucasian	21	84.0	42	97.7
Non-Caucasian	4	16.0	1	2.3
Age (years)				
20-30	6	24.0	12	27.9
31-40	13	52.0	19	44.2
41-50	4	16.0	9	20.9
51-60	2	8.0	3	7.0
61+	0	0	0	0
Relationship status				
In a marriage like rel.	17	68.0	32	74.4
Married	3	12.0	4	9.3
Single/never been married	2	8.0	4	9.3
Separated or divorced	2	8.0	1	2.3
Parental status				
No children	14	56.0	21	48.8
Children	11	44.0	22	51.2
Religious/Spiritual Affiliation <sup>a</sup>				
Roman Catholic	4	16.0	4	9.3
Agnostic	4	16.0	11	25.6
Christian (Disc. of Christ)	3	12.0	5	11.6
None	3	12.0	3	7.0
United Methodist	2	8.0	4	9.3
Atheist	2	8.0	4	9.3
Baptist	2	8.0	3	7.0
Episcopalian	1	4.0	3	7.0
Lutheran	1	4.0	3	7.0
Jewish	1	4.0	2	4.7
Presbyterian	1	4.0	1	2.3
Unitarian	1	4.0	1	2.3
Friends (Quaker)	1	4.0	0	0
Greek Orthodox	1	4.0	0	0
Buddhist	0	0	1	2.3
Islamic	0	0	0	0
Hindu	0	0	0	0
Other	2	8.0	7	16.3

Note. <sup>a</sup> Respondents could check all that apply; n's vary as not all participants answered every item.

Table 2 (Continued)

*Demographics of Interviewees Included in Qualitative Data Analysis (n = 25) and Those not Included in the Qualitative Analysis (n = 43) (Continued)*

Variable	Data Analyzed		Data Not-Analyzed	
	n	%	n	%
Years of Gen Coun Exp				
Novice (0-5)	10	40.0	17	39.5
Experienced (6-14)	10	40.0	17	39.5
Seasoned (15+)	5	20.0	9	20.9
Geographic region				
I (Northeast)	3	12.0	4	9.3
II (East)	7	28.0	8	18.6
III (South/southeast)	2	8.0	7	16.3
IV (Midwest)	7	28.0	11	25.6
V (Mountain)	4	16.0	5	11.6
VI (West/northwest)	2	8.0	8	18.6
Primary work setting				
University	10	40.0	19	44.2
Private hospital	8	32.0	8	18.6
Diagnostic lab	3	12.0	5	11.6
Government office	1	4.0	0	0
Group practice	0	0	1	2.3
HMO	0	0	1	2.3
Individual practice	0	0	0	0
Other	3	12.0	9	20.9
Specialty area <sup>a</sup>				
Prenatal	11	44.0	20	46.5
Pediatrics	9	36.0	12	27.9
Cancer	8	32.0	18	41.9
Specialty disease	3	12.0	6	14.0
Molecular	2	8.0	7	16.3
Neurogenetics	2	8.0	6	14.0
Teratogen	1	4.0	3	7.0
Infertility	1	4.0	2	4.7
Public health	0	0	0	0
Psychiatric	0	0	0	0
Other	3	12.0	10	23.3

Note. <sup>a</sup> Respondents could check all that apply; n's vary as not all participants answered every item.

call, but none seemed negatively affected as a result, and all of the participants responded to every interview question. It was this investigator's impression that every participant

approached the interview with openness, engagement, self-reflection, a conversational style, and a balance between seriousness and playfulness. As a result, most participants independently provided rich responses to the questions with minimal prompting or requests for clarification. Some interviewees commented on how beneficial it was to receive the specific questions for review in advance of the interview, explaining that the abstract nature of the questions likely would have caught them off-guard or unprepared otherwise. This researcher had the impression, however, that a few participants prepared written responses ahead of time, which resulted in truncated statements and a lack of spontaneity in some responses.

While most of the participants seemed to primarily draw upon an intellectual framework when answering the interview questions, many also provided emotional responses often centered on humor, hope, sadness, grief, frustration, gratitude and love. Some individuals also cried consistently throughout the interview while discussing experiences of personal loss and/or hardship, challenging patient scenarios, or feelings of empowerment. At times, it was difficult for this researcher to validate participants' strong feelings as an impartial interviewer rather than as a therapist, especially considering a majority of his training background is in therapy. Overall, this was a very personally rewarding experience to learn how to effectively balance these two important roles, in order to elicit credible data pertinent to the major aims of this study.

Three interview questions seemed to be more difficult for participants to answer compared to the rest of the interview protocol. Many participants expressed feeling confused with Question 3: "What types of issues related to *meaning* arise for you in your work as a genetic counselor?" Those counselors often stated the question (as well as its

accompanying prompt) felt too broad for them to answer outright without speaking to a more specific scenario (as elicited through questions 4 and 5). Other participants expressed uncertainty about how to answer Question 5 and the second part of Question 6: “Can you describe a situation from your work as a genetic counselor that has reaffirmed your personal views on *meaning*?” and “What aspects of your views on *meaning* have remained the same over time?” Some of these participants stated that it was much easier for them to identify challenges or changes in their views (rather than affirmations and stability) because the former tend to stand out more in their memory as distinct contrasts rather than merely an abstract continuation or strengthening of an already established belief.

### **Results of CQR Analysis of Interviewee Responses**

The interview results are organized according to six major thematic areas that closely align with the specific interview questions. Responses to three of the interview questions tended to share more similarities than differences and were, therefore, coded together. The six thematic areas are as follows:

1. General definitions of a meaningful life (Interview Question 1)
2. Sources and/or influences on one’s sense of *meaning* (Interview Question 2)
3. Specific contexts of *meaning* experienced within genetic counseling practice (Interview Questions 3, 5, and 7)
4. Specific challenges to *meaning* experienced within genetic counseling practice (Interview Question 4)
5. Changes in *meaning* over time (Interview Question 6)
6. Reasons for participating in this study (Interview Question 8)

Table 3

*Thematic Domain and Category Labels for Responses to Interview Questions 1-8 (n =25)*

<b>Domain/Category</b>	<b>n<sup>a</sup></b>	<b>Domain/Category</b>	<b>n<sup>a</sup></b>
<b>Gen Def of a Meaningful Life</b>		<b>Specific Contexts of Meaning Experienced w/in Gen Counseling Practice</b>	
Satisfying relationships	17	Helping others	23
<i>Individual relationships</i>	15	<i>General support</i>	21
<i>Sense of community</i>	4	<i>Imparting information</i>	17
Service to others	15	<i>Patient empowerment</i>	14
<i>Generally being helpful</i>	11	<i>Provision of resources</i>	9
<i>Being emotionally present</i>	7	Vicarious lessons	11
Fulfillment	14	Development of empathy	10
<i>Pursuing passions</i>	9	Appreciating individual differences	10
<i>General contentment</i>	6	Validation through gratitude	10
<i>Gaining knowledge</i>	5	Human connection	9
Making an impact	10	Intellectual challenge	8
<i>End of life reflection</i>	5	Resiliency	8
<i>Making the world better</i>	4	Miscellaneous	3
Work/life balance	7	<b>Specific Challenges to One's Meaning Experienced within Genetic Counseling Practice</b>	
Self-realization	5	Value conflicts	14
<i>Reaching potential</i>	4	Discomfort with loss/suffering	10
<i>Using skills/gifts</i>	3	Competing obligations and priorities	8
<b>Sources and/or Influences on One's Sense of Meaning</b>		Accepting that bad things happen	7
Health/illness/loss	23	Lack of control	7
<i>Personal issues</i>	15	Limited resources	2
<i>Others' issues</i>	8	<b>Changes in Meaning Over Time</b>	
<i>Lack of issues</i>	5	Deemphasized individuality	12
Religious/spiritual contexts	23	<i>Increased humility</i>	7
<i>Pos exp/background</i>	14	<i>Increased recognition of the value of relationships</i>	6
<i>Detachment</i>	8	General maturation	10
<i>Shift from religion to spir.</i>	6	Equanimity	7
Personal relationships	21	Help takes many forms	6
<i>Family</i>	18	Miscellaneous	5
<i>Friends</i>	9	<b>Reasons for Participating in this Study</b>	
<i>Cultural group</i>	2	Interest in the topic	15
Professional relationships	17	Importance of self-reflection	11
<i>Colleagues</i>	12	Paying the research experience forward	9
<i>Supervisors</i>	8	Desire that voice/issue be heard	4
<i>Patients</i>	2		
Personal values	9		
Biology	4		

Note. n<sup>a</sup> refers to number of comments

The corresponding domains and categories for these six thematic areas are presented in Table 3. Within each thematic area, domains and categories within domains are presented according to the corresponding interview questions and available question prompts for interviewees. Domains and categories are presented in descending order of prevalence. Select representative quotations for each domain or category are also provided verbatim. Of note, it was not at all uncommon for participant responses to be generic and/or complex enough, that one person's response to a particular interview question was classified into more than one domain and/or category. The data analysis team did note a few obvious differences between participant responses (e.g., those in a committed relationship identifying their partners as important sources of *meaning* and parents similarly identifying their children). More nuanced differences based on demographic variables such as gender, ethnicity and years of experience are described at the end of this chapter. However, these differences remain largely speculative due to the small numbers of individuals in certain demographic groups (e.g., males, non-Caucasian, etc.) preventing strong thematic differences across responses from being defined.

### **General Definitions of a Meaningful Life**

#### **(Interview Question 1: How might you define a meaningful life for yourself?)**

Responses to this interview question yielded six domains: Satisfying relationships, Service to others, Fulfillment, Making an impact, Work/life balance, and Self-realization. It should be noted that all of the participants were prompted with the following statement in order to elicit more detailed responses: "Please describe any examples of beliefs, values, and activities that provide you with this sense of *meaning*."

### **Domain 1: Satisfying Relationships ( $n = 19$ )**

Participants within this domain acknowledged the importance of generally satisfying connections with others as a major contributor to their sense of *meaning*. It should be noted that there was some overlap between this domain and the domain entitled “Personal Relationships” in the next section regarding “Sources and/or Influences on One’s Sense of *Meaning*.” Whenever a quotation was an obvious response to this first interview question rather than to the second interview question, or the participant spoke in broad generalities, the response was coded within this section related to their general definitions of *meaning*. This domain consists of two categories.

***Category 1: Individual relationships ( $n = 15$ ).*** The majority of participants provided definitions of a meaningful life that involve experiences of satisfying individual connections with other people such as family members, friends and coworkers.

*Relationships certainly. Because I think that’s probably the number one way that I can see the meaning in my life ... The most important thing in your life is people you surround yourself with, the family you were born into, and the people you pull into your circle.*

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*I think mostly [meaning] really has to do with my relationships. That’s definitely where I get my greatest sense of self-worth ... whether it’s at work or in my personal life. Having the sense that I’m bringing joy or happiness or a sense of peace. Or bringing something to the relationships that I have with other people ... People are number one in my life.*

**Category 2: Sense of community (n = 4).** Four participants stated that a meaningful life also includes satisfying, often big-picture, connections with broad communities of people.

*You certainly touch your family. But do you touch anybody else outside of that? I would hope that you can ... find some passion, some connections ... and as a community of humans, we're bigger than just ourselves if we just work together.*

**Domain 2: Service to Others (n = 15)**

Over half of the participants described how providing assistance, or specifically improving the lives of others, contributes to their sense of *meaning*. There are two categories.

**Category 1: Generally being helpful (n = 11).** A number of individuals spoke to how they gain *meaning* through serving others. Most of these participants remained relatively general in their responses regarding what being helpful or serving others might look like.

*The other main value is just making sure that I live a life where I'm giving back more than I take, like if I make some contributions where I'm helping people. Even in a minor way making something better for them ... there's something to be said for being able to make [someone's] life better.*

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*I think for me, it boils down to just helping other people. I know that's kind of broad but I think that that's the most important thing. And if I can help other people, whether it's personally or professionally, or whatever,*

*if I have something that I can add to another person, then that provides meaning for me.*

**Category 2: Being emotionally present (n = 7).** Several counselors identified that providing emotional support to others through listening and compassion results in a personal sense of *meaning*.

*... Connecting with people on an emotional level and helping them to either find meaning in their own experiences or helping them understand things [is meaningful].*

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*People need to hear themselves speak out loud. And also I think saying things out loud, even when it's stressful, allows people to begin the process of moving forward.*

---

*How you can help each other get through difficult times is what is important as a human.*

### **Domain 3: Fulfillment (n = 14)**

Over half of the interviewees described how participation in activities of interest, general feelings of contentment, and knowledge-attainment contribute to experiences of well-being and an overall sense of *meaning*. This domain consists of three categories.

**Category 1: Pursuing passions (n = 9).** Pursuing one's passions refers to the importance of enjoyable activities and hobbies as means of fostering feelings of engagement, enjoyment and purpose, thereby contributing to a deep sense of *meaning*.

*Experiences, like travel and appreciating different cultures [are meaningful]. Not just sitting at home on your couch. Being able to get out and see the world around you.*

---

*Vacations! Vacations and good food! (Laugh) And wine. ... [the] sorts of things that make life worth living.*

---

*Hopefully you do something [meaningful] that you don't want to bang your head against the wall every day that you go to work. (Laugh)*

**Category 2: General contentment (n = 6).** Some people emphasized how basic life satisfaction and experiences of well-being allow them to experience a more meaningful life.

*What's meaningful is when I can just take a step back from the hustle and the bustle and the "Let's get ready for school," or "Let's do all of our tasks," or "Let's check things off our list," and just be present. I don't always achieve it, but if I feel like I appreciated moments during the day, then I feel that that was what it was about.*

---

*... If I felt like I was leading a meaningful life, I know that I would be purely happy and content.*

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*... being content with your place in life. ... I think you need to be happy with where you are and what fills your daily activities. ... I mean [in]*

*whatever kind of space or time you want to talk about, whether it's for that day or that year; in whatever you're currently doing. Do you get any further gratitude out of that, or contentment?*

**Category 3: Gaining knowledge (n = 5).** Some individuals noted their drive to learn, be reflective, and enhance their general understanding of the world contribute to meaningful living.

*One aspect would be attaining knowledge. ... going to graduate school is not just something to do, not just for the career aspect, but also because I'm always seeking more knowledge ... Even now after graduate school, I'm just trying to attain knowledge.*

-----  
*I really like explanations. I like it when things make sense. I like specific answers.*

#### **Domain 4: Making an impact (n = 10)**

Many participants stated that a meaningful life involves leaving some sort of mark, impression or legacy on the world around them. There are two categories.

**Category 1: End of life reflection (n = 5).** A few individuals described a meaningful life as one that involves feeling satisfied with one's legacy as death approaches.

*I think most about this question in the sense of what would you want people to see at the end of your life? And I was thinking that what I'd love to be able to have accomplished throughout my life is for people to feel like I was really there for them, especially when it counted. [That] I was a*

*dependable, loving, trustworthy person that made them better for having known me, because that's certainly how I feel about a lot of people that I'm close to in my life.*

---

*I always joke to my husband that nobody stands up at a funeral and says, "He was really good at watching TV all day." (Laugh) So, I think it's what you do, and the people you do it with, that make a difference. I mean I still think a lot about what people are going to say when you die at your funeral and what are they going to be left with once you're gone. I use that thought a lot to guide my decisions or my take on life.*

**Category 2: Making the world better (n = 4).** Four participants spoke to how a meaningful life involves making at least a modest impact on the world around them.

*... A meaningful life is a life where you have the opportunity to make a difference or make an impact; be that on one person or on a population ... I think that a meaningful life for some individuals would be to make a dramatic change in the whole world. For myself, my goals are much more modest. I would like to be able to make a difference in the lives of some people.*

---

*... leaving the world a better place than I found it. And, as far as that goes, it doesn't have to be that I do something enormously huge. It could be as simple as having children who are good people and who do good things.*

### **Domain 5: Work/life balance ( $n = 7$ )**

A few individuals described a meaningful life as one that includes striving for a balance between personal and professional endeavors, so as not to become discontented, overwhelmed, or one-dimensional. There are no separate categories.

*Since I started working, I get a lot of value and personal satisfaction and joy out of my job and my work. But I also find that I tend to sacrifice personal time for my job. And I'm wanting to be less willing to do that, especially over time.*

---

*I could be really happy not working, living at home, having friends, seeing my family, and stuff like that. But there would still be a part of me that would really want to be working at least part-time and contributing to this other world that I am aware of. And so, somehow having a balance of those two things I think is really important for me to have a meaningful life.*

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*... Women kind of define their lives a lot by their children, more than I would want to ... You know, I am really looking forward to having kids and to being a mom **and** [emphasis added] to being a working parent.*

### **Domain 6: Self-Realization ( $n = 5$ )**

Some participants emphasized how efforts towards personal improvement and capitalizing on one's inner strengths contribute to a sense of *meaning*. This domain consists of two categories.

**Category 1: Reaching potential (n = 4).** Four individuals discussed how improving oneself through goal-setting and personal achievement contribute to their sense of *meaning*.

*... I started to look at the traits that my children had and started to think about aptitudes and interests and how you can reach your personal maximum given the person that you are. I want to use all of the capabilities that I have. So, only if I'm stretched am I really tapping into all the capabilities that I have [do I have a sense of meaning].*

**Category 2: Using skills/gifts (n = 3).** Three individuals also described how tapping into their strengths and capitalizing on their skills contribute to their sense of *meaning*.

*... I kind of feel like that's what gives meaning to your life ... [that is] recognizing your talents and giving to others through those talents.*

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*... I think my skills of empathy and analytical skills, and other traits make me a good daughter and a good mother, a good friend, a good volunteer at school.*

### **Summary of Responses Related to General Definitions of a Meaningful Life**

The vast majority of participants described satisfying relationships as central to their definitions of a meaningful life. For many, giving and receiving support with family and friends is what provide them with a sense of purpose and satisfaction. This aspect of *meaning* is often tied to additional desires to be of service to others and to make a lasting impact (however modest in scope) on the world. Some genetic counselors experience the

realization of these additional desires when they feel as if they are improving the lives of specific family and friends on an individual level, while for others it is experienced when they feel they are able to be generally helpful on a more community-wide level. Some participants spoke about engaging with this sense of *meaning* while interacting with others in the here-and-now, whereas other participants spoke more prospectively about how they will want their lives to have looked when they are approaching death.

Over half of the participants mentioned they know they are living a meaningful life when they feel personally fulfilled through individual hobbies, personal passions, and a pursuit of knowledge. On a more individual level, participants also spoke to the deep sense of *meaning* that comes from setting personal goals and using their skills to both achieve those goals and reach their full human potential. Finally, approximately one third of the interviewees spoke of the importance of balancing their work and their home lives so as not to lose focus on either important domain. Overall, it seems participants generally defined their personal sense of *meaning* as a delicate balance between the outward expression of satisfying relationships and the inward experience of fulfillment and self-realization.

### **Sources and/or Influences on One's Sense of Meaning**

**[Interview Question 2: Some people mention the following as sources of influence on their views on life's *meaning*: a) personal relationships; b) professional relationships; c) religious/spiritual/existential beliefs or practices; d) personal experiences of health/illness/loss; and e) having children. Can you talk about whether/how each of these has been influential on your own views on life's *meaning*?]**

Responses to this question yielded six domains roughly in line with the prompts provided in the interview question itself: Health/illness/loss, Religious/spiritual contexts, Personal relationships, Professional relationships, Personal values, and Biology.

**Domain 1: Health/illness/loss (n = 23)**

All but two participants described how they have redefined their sense of *meaning* during or after an important struggle with illness or loss for themselves or others. For many, this redefinition resulted in increased empathy or understanding about life and loss. Three categories reflect their responses.

**Category 1: Personal issues (n = 15).** A majority of participants described how their own experiences of health concerns or loss have contributed greatly to an increased sense of empathy for others.

*I do have much loss in my life ... [I have lost] many friends [and] all kinds of things ... [and it] has expanded my empathic skills. I'm very clear that it's not that I'm sympathizing, but I think having had that life experience gives me a broader platform to hear stories of loss.*

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*Right after I got married I got really sick. (Crying) And I quiver when I talk about this. It taught me about love in a way that I never understood before ... It changes your perspective of what other people are going through and what you might be able to do for those people and how you might contribute to make their lives a little bit better ... It kind of throws everything off, and you know everything that you knew before that time is just totally different.*

**Category 2: Others' issues (n = 8).** Some individuals spoke about how witnessing others' health concerns or loss has contributed to an increased sense of appreciation of their own health or their ability to experience resiliency themselves.

*My mom's sister, passed away from a long bout of breast cancer. She was an amazing woman, and so I use her as another example of how you can face challenges with an open heart and a smile and an optimistic spirit ... For her, cancer wasn't the center of her life ... And that I think was a really good lesson, that yes, we all face obstacles but they don't have to overwhelm us and be the only thing that we concentrate on.*

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*I have had many friends who have struggled with many illnesses, cancer, of course being the common one. And watching the strength it takes to really fight against a bad disease ... And there's always the question, "Could I possibly be that strong in a similar situation?" So, it's both modeling and just wonderment that people can continue to put one foot in front of the other when everything else seems to be caving in around them.*

**Category 3: Lack of issues (n = 5).** Five counselors mentioned they have not experienced any notable issues with health concerns or loss. For some of them, this general lack of issues has provided a sense of additional *meaning* through increased gratitude or appreciation.

*I guess lack of illness or tragedy in my family and my loved ones [has been meaningful] .... It's more of the view that life is uncertain every day,*

*that things like that do happen to people, and more of the realization that we are fortunate people.*

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*I've been pretty blessed on that front. I mean I'm very thankful for my good health and my family's good health, but I haven't had really any experiences with that, so I can't say that has really formed my feelings on meaning of life.*

## **Domain 2: Religious/spiritual contexts (n = 23)**

All but two participants spoke to the influence religious and/or spiritual foundations have had on their current sense of *meaning* or purpose. For some participants, this included a strong affinity for religious practice throughout their lives, while for others it involved either a detachment from religion and/or development of a broader spiritual identity over time. This domain contains three categories.

***Category 1: Positive experiences/background (n = 14).*** Over half of the interviewees described how embracing their religious backgrounds and/or current practice was central to their overall sense of *meaning/purpose*.

*I would define a meaningful life as one that had God at the center of it ... it would include ideally daily quiet time for myself – for spiritual introspection.*

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*For me, [my Christian background] is the center. I'm answerable to a higher power, and so it helps me to have a starting point; a grounding in what sorts of concepts are appropriate and expected and reasonable for*

*my day to day life. Loving other people and being respectful and all that stuff. That comes from there.*

**Category 2: Detachment (n = 8).** Some individuals mentioned past religious backgrounds/experiences, in some way, as unpleasant or unsatisfactory. For most within this category, their unpleasant experiences usually led to denouncing or moving away from formal religious practice altogether.

*I did not find comfort in my childhood structure, which was very anti-woman.*

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*When I was younger, I was very active in a religious upbringing ... [And] actually I feel it shaped me to go away from religious beliefs. It didn't draw me in. I did not find any comfort from it. It made me a little bit angry because there were so many rules and so much [hypocrisy] ... that just brought feelings of anger.*

---

*I'm a little bit troubled by [using] right-wing, evangelical religion to support telling other people how to live their lives ... I work in an environment with a few physicians where every time there's an issue, we'll pray about it. And they're very vocal and open with their religion, and I'm a little more private with my personal faith. I feel like the actions that you do speak much more than the scriptures that you can quote ... I'm just hesitant to lay the whole meaning of life on the Christian values and God says we should act this way, so therefore we should.*

**Category 3: Shift from religion to spirituality (n = 6).** A few participants commented on finding a deeper sense of *meaning* over time within broader spiritual practices compared to those of organized religion, whether or not they fully detached from religious participation.

*I had a good upbringing in the church, but my own religious beliefs are not organizational at this point. I still believe in many of the tenets of my religion, but I find organized religion doesn't always exhibit the values that it's purported to, or that it's representing.*

**Domain3: Personal Relationships (n = 21)**

A large majority of counselors described how relationships within their personal lives have served as historical sources and/or current influences on *meaning*. As mentioned previously, there was some overlap between this domain and the earlier “Individual relationships” domain, which concerns general definitions of *meaning*. The majority of quotations within this domain are taken from participants’ direct responses to the second interview question. There are three categories.

**Category 1: Family (n = 18).** A great many participants described how their immediate family (including children) and extended family relationships serve as a powerful source of *meaning* and purpose.

*I can pretty much divide my life into BC (before children) and AC (after children). (Laugh) It just gives me so much more perspective on how silly so many of the things you worry about before kids are ... Having kids puts things into perspective and you know, constantly what I do is “Ok, does this matter? Does this matter?” ... Does it matter in this moment, whether*

*this happens or that happens? And, you know, most of the time, the answer is “No.” None of that matters. It’s the bigger things of long-term growth and development and joy [that matter].*

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*My personal relationships have been very very important in [shaping] my beliefs. I have a partner who has led by example. As did my mother in terms of always being there, trying to do the best they can for anybody and everybody that they come across. On the flipside, my relationship with my father was a bit more acrimonious. And despite his being a pretty difficult guy, and giving me some negative examples over time, I think that deep down his interest in being kind and caring, despite sometimes being very well hidden, was important.*

**Category 2: Friends (n = 9).** A number of individuals emphasized how their friendships serve as powerful influences on their sense of *meaning* over time.

*Most of my personal [friendships] are fairly strong with a few people. So, I have close relationships with a small number of people who I could call on at any minute. And it really gives you that sense that you must be a good person to have these people who would be supportive of you in situations when you need them.*

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*I’m not one of those people who has a million friends who I do things with ... I guess in my personal relationships, I tend to stick with fewer people*

*who I'm closer to rather than have a lot of surface friends ... and just giving mostly unconditional acceptance. (Laugh)*

**Category 3: Cultural group (n = 2).** Two counselors noted that their identification with their broader cultural group provides them with a sense of *meaning*.

*So, culturally it's just a gratitude for my roots really. And that has an influence on who I like to help. That's not to say that I don't like to help other religions or other cultural groups. I simply have more enjoyment when it comes to patients of my shared cultural background.*

#### **Domain 4: Professional Relationships (n = 17)**

Most participants spoke to how their relationships at work or within the field of genetic counseling serve as important sources of influence on their sense of *meaning* over time. It should be noted that depending on the extent to which participants said their colleague relationships are also friendships, they were coded respectively. This domain yielded three categories.

**Category 1: Colleagues (n = 12).** Approximately half of the individuals described their coworkers, or associates within the broader profession, as important influences on their overall sense of *meaning*.

*Genetic counseling is one of those professions where there are pretty inspiring people in the field. And definitely a lot of the pioneers in this work have been quite an inspiration to me; in terms of how to do the right thing for families, and how to feel good about yourself at the end of the day. And there have absolutely been people in the field as well who have given me the inspiration to a) continue doing it, and b) do it the right way.*

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*In the years that I've been practicing, I've really discovered how important it is to have good positive relationships with the people who I work with. Just because the profession itself is somewhat draining at times, and it's good to have some people to help just say, "Ok, what we're doing is meaningful." And that it is an important thing to help these families. And that when it's hard for us and draining for us, [we need to remind ourselves] that it's something that they're living with regularly, so it's even harder for them. But then also having people just to laugh with and to encourage and to be encouraged by at work [is meaningful].*

**Category 2: Supervisors (n = 8).** Some counselors emphasized how their direct supervisors, professors or mentors have served as powerful influences on their sense of meaning over time.

*I learned so much from [name] who was the coordinator. Just about being flexible and finding alternate ways to the same endpoint that maybe you hadn't foreseen ... So, I definitely think of her as a role model and an example.*

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*I worked with a mentor [who] said to me, "You have to remember that you did not create this bad news." And [that] was really changing for me in that ... I [might] deliver bad news, but I do not create it ... That really made a huge difference for me in terms of thinking I'm not really part of the bad news. I can be a more positive aspect of what's happening.*

**Category 3: Patients (n = 2).** Two individuals said patients serve as important influences on their sense of *meaning*. Of note, participants who described how their patients provide them with specific opportunities to vicariously experience how they might themselves handle a certain situation, or to appreciate resiliency in others, were coded in those respective categories in the next section.

*There are times in peoples' lives, very vulnerable times, when you are connected to this bigger picture of what life's all about, what's important, your relationships and your mortality. And you tend not to focus on those smaller details of life that tend to fill your day. And so I think for me working with primarily breast cancer patients and family members of cancer patients who are grappling with these issues of grief and loss, as hard at it is, keeps me plugged in to that bigger picture.*

**Domain 5: Personal values (n = 9)**

Several participants described personal values and/or beliefs that have influenced their idea of meaningful living over time. There are no separate categories.

*One thing I have been trying to work on is [my value of] being more specifically thankful for things. And to try to get our family to be more thankful for things; specifically to articulate what we're most thankful for.*

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*[The value of] how you treat people and your integrity [is meaningful to me]. Do you treat everyone the same, or do you treat your family one way and your higher-ups another way and the people that report to you another way?*

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*I think that morally, I feel like you're obligated to raise [children] and support them and feed them and try to provide for an education ... [And] I think that I'm obligated to do more than just study the Bible. I'm obligated to help other humans.*

**Domain 6: Biology (n = 4)**

Four interviewees expressed a belief that “nature” produces innate traits and/or behavioral patterns that influence their sense of *meaning*, beyond the scope of environmental influences.

*[My sense of meaning] is probably a combination of the way I grew up and ... the way I was born basically. Some experiences have happened to me, but also just the way that my brain is wired.*

**Summary of Responses Related to Sources and/or Influences on One's Sense of *Meaning***

Interview Question 2 asked participants to focus on some of their important sources and/or influences for their sense of *meaning* over time. The interview question itself prompted everyone to consider certain realms of potential influence. The vast majority of genetic counselors stuck exclusively to the prompts, thus likely limiting the potential range of responses they may have provided otherwise. Nevertheless, the participants provided many rich examples of specific sources of their *meaning*. The majority provided examples of personal issues of illness or loss throughout their lives as an important contributor to how they view and/or approach their lives. Many have directly experienced sickness or loss, while others have primarily witnessed it indirectly

through family members or friends. A handful of counselors stated they have not yet directly experienced much loss in their lives. The majority of all three sub-groups described these experiences as powerful sources of empathy, appreciation, and gratitude.

Most participants also spoke to religious and/or spiritual contexts as important sources of *meaning*. Approximately half described their positive upbringing or current experiences in religion as strong influences, while the other half spoke of either a negative detachment from religion or a more subtle shift to spirituality as an important influence on how they experience *meaning* in their lives. Similar to the relationship domain described in participants' definitions of *meaning*, they also spoke of specific individuals who have served as influences over time. The majority identified family members, whereas some mentioned friendships and/or their broader cultural group as important sources of *meaning*. A number of participants provided responses to this question beyond the specific interviewer prompts. Some mentioned that long-standing values and/or a sense of moral duty have provided them with a lens through which to experience *meaning*. And finally, a handful of participants suggested it is simply their biological make-up that makes them experience *meaning* in different ways than others. Overall, this interview question seemed difficult for participants to consider without the scaffolding of available prompts. Nevertheless, they provided many rich examples, and this was the interview question for which some participants became noticeably emotional and increasingly self-reflective when responding.

### **Specific Contexts of *Meaning* Experienced within Genetic Counseling Practice**

This section includes domains, categories, and examples of participant responses to three specific interview questions. Previous attempts to extract separate domains and

categories for each of these questions proved difficult and a bit arbitrary, as so many responses reflected similar themes.

**[Interview Question 3: What types of issues related to *meaning* arise for you in your work as a genetic counselor? Prompt: What are the contexts in which *meaning* (in as far as you have defined it for yourself) arises in your work?**

**Interview Question 5: Can you describe a situation from your work as a genetic counselor that has reaffirmed your personal views on *meaning*? Prompts: What was the context? What issues of *meaning* arose? How did you address this situation for yourself?**

**Interview Question 7: What personal *meaning* do you derive from what you do as a genetic counselor? Prompts: What does it mean to you to be helpful in your profession? What do you get out of what you do?]**

Nine domains were extracted from responses to the three interview questions: Helping others, Vicarious lessons, Development of empathy, Appreciating individual differences, Validation through gratitude, Human connection, Intellectual challenge, Resiliency, and Miscellaneous.

**Domain 1: Helping others ( $n = 23$ )**

All but two participants emphasized experiencing *meaning* through their clinical work as genetic counselors when they feel they are directly improving the lives of others in some way, which helps validate their general desires to help individuals or improve the world (as expressed in responses to previous interview questions). This domain contains four categories.

**Category 1: General support (n = 21).** The vast majority of individuals mentioned experiencing *meaning* within their work by affirming another's experience through active listening, compassion and being emotionally present.

*I really think what meaning comes from is being able to point to a specific person and say, "I personally made their life a little less sucky."*

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*I guess it brings meaning into my life to sometimes be the one that can be there as an outlet. It doesn't make the pain any less but at least it makes it a little bit easier for them to have a sounding board. I know as a genetic counselor, sometimes my job is to be the whipping post. The person on which a family can be angry and can rail against [for] everything that's happened or is happening ... And fortunately, occasionally, it's to share in the happiness of accomplishments of children who weren't expected to have a lot of accomplishments.*

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*[My grandmother used to say] "The joy that isn't shared dies young." But I think I try to take the sort of the reverse of that almost and say, "The pain that isn't shared festers." And so I try to just sit with the patient in a seemingly meaningless and bad situation and just be with them. And to know just the act of being with them and sitting with them in their pain is helpful.*

**Category 2: Imparting information (n = 17).** A large number of counselors identified educating patients regarding diagnosis, disease-etiology, and/or biological risk,

for the purpose of enhancing knowledge as contributing to their sense of *meaning* within their work.

*I'm fascinated with how I can teach individuals about [genetics] when they don't have very strong biological backgrounds. So it's fascinating to me to find ways to teach it ... and I just love it. If they can grasp the concept after I leave, then I've done my job.*

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*... for those families who are really feeling alone, it's a huge gift to be able to give them an answer.*

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*... whenever there's a patient who starts off and their comments are such that you know they either don't understand or aren't aware, it brings meaning to your life to be able to educate.*

**Category 3: Patient empowerment (n = 14).** Just over half of the participants said their deep sense of *meaning* comes from finding ways to strengthen their patients' sense of autonomy so that they feel more in control of their situations, and/or are able to make better-informed decisions.

*... if I can give them a sense of even a glimmer of understanding or control through that understanding, then I feel like I have provided something meaningful for them.*

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*... helping to empower families [is meaningful]; that they feel comfortable in knowing that they can ask for help, in knowing that it's their health, that*

*they're in charge, they get to say what happens and what doesn't happen. And that they already have the wisdom and the strength to make decisions. It's just a matter of making sure that they know how to tap into that strength.*

**Category 4: Provision of resources (n = 9).** For several individuals, *meaning* within their work occurs when they are able to meet their patients' individual needs by connecting them with support, specific procedures and/or services.

*I think when you have a positive influence [is meaningful] ... when you realize something you've done either made their life easier or helped prevent them from getting some sort of horrible problem because something was caught earlier because you recommended a certain procedure.*

-----

*I remove obstacles in the health care system. If I can play a role in getting a patient what they need because I know how to work through the system, I know where to send them to make things happen or to get a referral, that goes into my meaning as a genetic counselor.*

**Domain 2: Vicarious lessons (n = 11)**

A number of counselors expressed that difficult patient situations challenge them to think about how they might deal with similar scenarios in their own lives and that such prompted self-reflection results in learning more about themselves in the process.

*You can acknowledge to yourself what you would do. "Ok, if I were in this situation, now that I've been working with this family, I know that I would*

*choose this.” And that’s, you know, very enlightening as I go through my career. Every situation has some kernel that I can pull out.*

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*I saw a lot of people who had done everything right, you know? ... And here they were in their 30’s sitting in front of me with a terminal diagnosis of cancer because they had inherited a hereditary cancer. And that really changed my view of trying to be healthy all the time ... I think that really changed my view of nobody can predict what’s going to happen. Whatever will be will be. And you just have to do the best you can. You can’t beat yourself up for not being perfect all the time ... Those sorts of things have definitely made me more of a person who tries to live in the moment and make everyday count.*

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*I’m sure every genetic counselor, when they’re having children, because they see so many children with disabilities and genetic conditions, considers what would be the meaning for them ... So, that’s something that I have considered ... But if you’re not dealt the cards that you expect in life, how do you turn that into something where your life doesn’t spiral into this big black hole that it seems to be for some patients?*

### **Domain 3: Development of empathy (n = 10)**

Some counselors commented that difficult situations within their work have contributed to a deep sense of *meaning* by providing opportunities to question their own

personal views, see multiple perspectives, and remain focused on the patients' best interests.

*I put myself in their shoes and say "Ok, they're afraid, they don't understand what this is and I might not have seen that as being something as very difficult, but it's not about me right now" ... It kind of challenged me to think differently about my own views about termination and how people arrive at that decision.*

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*I think [meaning] is more in the context of speaking with a patient who has a very different life experience or social situation than I have. I think for that moment of a half an hour, or however long it takes with that patient, I think I have to try to sort of leave where I am coming from and see things the way they would see them or feel them or to see where they are coming from.*

#### **Domain 4: Appreciating individual differences (n = 10)**

Some participants experience *meaning* when they come to understand the diversity in patient backgrounds/experiences and how unique and interesting each case is in its own right.

*I feel like every parent is different. Every patient coming into your office doesn't want to feel like a patient you've seen every day. They're special. It might be their very first baby and there's something wrong with them. You should be there emotionally, even if you've seen it a hundred times*

*before. I definitely try – that’s the way I keep myself interested, in seeing every case as new.*

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*I feel like being helpful is creating a personalized approach to assist them to make a decision that is most appropriate for them, not a cookie cutter thing – it would not be helpful if I just did the same thing for every person. To create something that is personalized and hopefully most impactful for that one person [is meaningful].*

#### **Domain 5: Validation through gratitude (n = 10)**

Many interviewees described *meaning* as coming from the positive feelings and validation they experience when patients say thank you with their words or actions.

*... the thing that aligns the most [with meaning], or makes me feel that it aligns the most, is when patients or their families are grateful for what we have done for them. It’s when they say, “Thank you for working with me,” or “Thank you for helping me with this,” or “You helped me.” And I guess just hearing that ... that’s what I wanted to do, that was my goal. And they’re telling me that I did it.*

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*I think that the thing that constantly rejuvenates me and gives me a sense of meaning ... is anytime a patient says thank you ... They’re dealing with one of the most awful times in their life, like dealing with a baby that’s going to die or have to deal with lifelong disability problems. And when*

*then tell me that I've helped them through it, that's just the best feeling in the world.*

**Domain 6: Human connection ( $n = 9$ )**

A number of genetic counselors explained how their work provides them with a sense of *meaning* through opportunities to connect in substantial and memorable ways with patients and colleagues, usually through stories and a shared mission.

*... and it's nice for me because I like having that personal connection with patients, and that goes back to the whole relationship thing that I mentioned before. It really isn't just about showing them a punnett square.*

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*I enjoy meeting each new family and hearing their story. It's a new glimpse into a different life that I haven't experienced before ... That's one of the things that I love about my job. Just meeting each new family and hearing their story and learning about their family and their history.*

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*I think [meaning] is more of what I see long-term, like at Christmas time. We're inundated with Christmas cards, family photos, people telling us that they've gone on and things are going well. And I see that pile of Christmas cards, and I think how lucky we are that people still feel connected to us because we are a community genetics program.*

**Domain 7: Intellectual challenge ( $n = 8$ )**

Several participants described deriving *meaning* from the mental stimulation that comes from feeling they are learning, engaged and productive while working. A number of these counselors mentioned the stimulation that comes directly from mastering a complicated science.

*And then there's the joy of challenging my brain with the field of genetics. I love learning about each new disorder. And as each new discovery is made about how this interacts with that and how this will predict that, it energizes me. It stimulates my brain and makes me feel like I'm not just in a field where nothing ever changes.*

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*Genetics is really complicated! And so it gives me personal meaning to know that I am using all of the neurons that are up there [in my brain]. I'm trying to tap into all of them every week, every day ... And if I believe that the work that I do is helping somebody else, then I don't feel selfish about being totally indulgent in diving into such a niche'y part of science that I'm really interested in. And so that belief of helping somebody with my knowledge gives me permission to just be totally geeky about it.*

*(Laugh)*

### **Domain 8: Resiliency (n = 8)**

Several counselors mentioned their increased awareness of and appreciation for people's inherent resilience provided them with a sense of *meaning*. A few of these participants focused on patients' abilities to bounce back from adversity, whereas others

focused on patients' abilities to not only bounce back but actually grow stronger through their suffering.

*There's an admiration as to how those people manage to get through [suffering] and handle it with grace and dignity and a positive attitude. And it's just quite amazing to me, the strength of character that some people are able to show.*

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*You watch a family go through something horrible and you think, "This is a bad thing." And you think, "There's nothing I can do to help them, and this is a bad thing" ... And you will see change that that family has undergone as a result of their negative, horrible, bad experience. It kind of makes sense. I mean, yes, it was horrible. But look at all of the good things that have happened because of this one bad thing ... You'll see them at a support group or a fund-raiser and you will see how they have helped so many people, so many other families because of their tragedy ...*

*Sometimes tragedy engenders growth and helps a family.*

**Domain 9: Miscellaneous (n = 3)**

Three genetic counselors provided responses of how they experience *meaning* within their work that could not otherwise be classified. These variously include comments about having opportunities to see the underlying positive qualities in others and to provide meaningful experiences for other genetic counselors.

*I just love the fact that you get to see people closer to who they are, and people aren't as brutish as you might make them out to be on the street. So it kind of reaffirms that whole thing that people are inherently good.*

### **Summary of Responses Related to Specific Contexts of *Meaning* Experienced within Genetic Counseling Practice**

Virtually all of the participants emphasized opportunities to help patients as the primary context within their genetic counseling practice that allows them to experience a deep sense of *meaning*. The majority identified as personally meaningful, situations in which they can offer general support to their patients (e.g., listening, supporting, caring), and those in which they can provide their patients with important information (e.g., biology, testing protocols and risk management). Some counselors also emphasized the exciting intellectual challenge of balancing both of these important roles to provide individualized approaches tailored to unique patient needs. A majority also described experiencing *meaning* within their work when they are able to contribute to patient empowerment through education, provision of resources and advocacy. Some counselors expressed that a sense of *meaning* feels most present when they receive direct expressions of gratitude from their patients, which allows them to feel successful and validated in their intentions to help others. In addition, it was common to hear from the participants that their work directly increases their empathy for others through exposure to diverse patient issues and that the resiliency patients and families often demonstrate in the face of illness and adversity greatly contributes to their own sense of *meaning*. Participants also spoke of how patient experiences tend to spark their own internal self-reflection vis a vis how they themselves might deal with similar situations in their own

lives. Overall, a number of the counselors spoke of feeling blessed to have the opportunity to work in a field that offers such intimate human connection with consistent opportunities to help patients in need.

**Specific Challenges to One's *Meaning* Experienced within Genetic Counseling Practice**

**(Interview Question 4: Can you describe a situation from your work as a genetic counselor that has challenged your personal views on *meaning*? Prompts: What was the context? What issues of *meaning* arose? How did you address this situation for yourself? )**

Responses to this interview question yielded six domains: Value conflicts, Discomfort with loss and suffering, Competing obligations and priorities, Accepting that bad things happen, Lack of control and Limited resources.

**Domain 1: Value conflicts ( $n = 14$ )**

Over half of the participants described how their sense of *meaning* has been challenged when they work with patients whose values are noticeably different than their own. A few of these counselors elaborated, by emphasizing the importance of striving to manage their discomfort in order to allow patients to make autonomous decisions.

*Yeah, I think that is the most difficult part. [That is] often times when I'm working with patients who in my interpretation of the situation ... I just get the feeling that parents maybe just aren't doing enough for their child ... Basically the idea is that they just seem like shitty parents. And I guess some sense is me judging them, but it's just that I guess it's difficult at*

*times to help people and want to serve people when they don't want to do anything for themselves.*

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*... I understand when couples are aware of what they are able to do and they choose not to continue a pregnancy because of something serious. The ones that I find challenging are when I don't think it's that big of a deal. And they go ahead and choose to terminate over something that I see as less severe, you know? And that's hard for me ... I know their decision is the one they're making that is right for them. But sometimes it is hard for me to get to the place where they are, because I think that whenever that happens, I'm like, "Agghh. It's not that bad!"*

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*... they made a decision to continue the pregnancy because it was a male, and they wanted a son, and I could feel ... [like I was] shutting down ... How can the parents know that this child is going to go through the same medical problems and feel okay with that? And will they ever disclose that to him, or will they allow him to get his own testing when he's over eighteen? That really went against my idea of people making the best decision in the best interest of their child.*

**Domain 2: Discomfort with loss/suffering (n = 10)**

A number of genetic counselors shared that their sense of *meaning* within their work is challenged when they feel uncomfortable with the pain and suffering of their

patients, or with the fact that there is so much pain in the world. Examples in this domain range from countertransference to empathy, and sometimes a mixture of both.

*I saw an inpatient who was given a few weeks to live, and I really did not want to go see him. It kind of contradicted my view of the meaning of my life to help individuals. I was just really scared of seeing him dying. When I went there, I almost hoped that he was asleep and unavailable. And when I got there, he was. I was ecstatic about that, and I feel guilty about it now ... Loss is something that is still difficult for me to deal with.*

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*I mean, I guess I sometimes question if I am supporting a patient because I'm raising their anxiety level. They didn't really worry about it. And now because I have to explain all of this, I'm creating anxiety instead of reducing it.*

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*[I believe that people generally do not want] to have limits on [their lives] ... And so if I see that there's something that's going to be limiting, then that is something that I find sad ... I think about it afterwards. And I reflect. And I just acknowledge it myself. And, you know ... I just acknowledge that this sucks!*

### **Domain 3: Competing obligations and priorities (n = 8)**

Several counselors provided examples of how their sense of *meaning* is challenged when they feel torn between conflicting expectations of patients, supervisors,

medical doctors, society, and/or their personal lives. For some participants, this seems to have even resulted in a feeling of hopelessness around the current situation improving.

*Lately, [I have] been struggling more with the day to day mundane insurance crap and all that comes along with being a genetic counselor. Just having to [remind myself], “Okay, all those little things that I do in my job are in some way going to help.”*

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*I’m challenged by the societal infrastructure [in which] people live and experience illness. And that really, if it’s anything, it’s just how there’s this sense of unfairness around access to health ... And I’m thinking, isn’t this the craziest story? She [the patient] just told me how much she loves taking care of these people and how we need more people out there taking care of people in their homes. And she’s having to cut back her hours maybe so that she can get adequate healthcare!*

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*Right now I’m going through a decision whether to continue working at my current job because of the lack of balance ... I’ve been working twelve, fifteen hours a day, and not having a moment for my family because anytime I am home I need to take care of myself by sleeping or something. And it’s just to the point where I kept thinking “It’s going to stop, it’s going to stop.” Or, “Once this is done, once that’s done.” But it’s never done. (Crying) So that’s definitely something that I’ve had to weigh, and decide what the most important thing is for me. That’s part of the reason*

*why this has all been going on over the last several months, and you actually caught me on the day that I think I've made a decision [to quit my position].*

**Domain 4: Accepting that bad things happen (n = 7)**

Some participants expressed that their sense of *meaning* is challenged when they recognize the suffering in the world. They described examples of how they work to acknowledge this reality without feeling defeated.

*Okay really, how much did they really need to go through that? But then just watching them, and they have a very strong faith. Watching them go through that and their witness (e.g., the help that they provide) to many, many other people. And right now, things are going well and fairly stable so I look back and say, "Yeah that was bad, but meaningful."*

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*Stuff happens. And I don't think that God causes it to happen to anyone. Babies are lost. Disease happens. Cancer happens. It's just biology, I believe.*

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*Life is not fair. And that's a sucky thing.*

**Domain 5: Lack of control (n = 7)**

Feeling limited in one's ability to inspire change on an individual and/or discipline-wide level challenged the sense of *meaning* for several counselors.

*It's the physical suffering of the child that's difficult and then the emotional suffering of the whole family who is trying to support them and*

*care for them and hopefully cure them. In that situation, [I feel] pretty helpless to do anything.*

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*[It is challenging] when a patient will shut down and almost refuse to make a decision. For me, that gives a very unfulfilled need of wanting to help that patient work through that decision-making process ... I really struggle with the patients not needing my meaning, and yet it is all about the patient, but I am there to help. And if they're not going to let that happen, it's extremely frustrating.*

#### **Domain 6: Limited resources ( $n = 2$ )**

Two individuals commented that their sense of *meaning* feels challenged by some of the general limitations inherent to the field of genetic counseling, compared to other fields of practice.

*In my setting, the prenatal setting, you have very limited interactions [with patients]. You never actually spend more than an hour with one person ... I don't get a lot of follow-up visits, and so it's a very short relationship that is built. But I still value it.*

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*You know, our profession isn't well supported financially ... so, we aren't able to bill for our services yet. And therefore, we're just a vast expense in most senses ... Not a lucrative field and [that is challenging].*

#### **Summary of Responses Related to Specific Challenges to One's *Meaning* Experienced within Genetic Counseling Practice**

When asked to provide examples of specific challenges to their sense of *meaning* experienced within their clinical work, the majority of participants described value conflicts. A number of participants expressed that it can be challenging to work in prenatal settings when they disagree with patients' reasons for terminations or conversely, for continuing a pregnancy. Also prevalent were examples that centered on genetic counselors' general discomfort with the pain, loss or suffering of their patients and families. It was not uncommon to hear that the extent of this suffering almost "forces" genetic counselors to accept that bad things happen to good people and life is not fair. Some counselors appeared to have reconciled themselves to this reality, while others expressed a greater degree of helplessness and, in a few cases, hopelessness, through their desire to fulfill their most basic intentions to serve others. Relatedly, some participants provided examples of competing obligations within their work (e.g., insurance pressures versus individual patient needs, long hours at work pulling them away from their families) as well as limited resources within the field as specific challenges to their views on *meaning*. Most of the examples seemed to reflect barriers to their professional roles.

### **Changes in *Meaning* over Time**

**(Interview Question 6: Let's take a little time to explore your current views on *meaning* as discussed so far, and compare them with when you first started your work as a genetic counselor. What aspects of your views, if any, have changed since you first started your work in this field? What aspects of your views, if any, have remained the same?)**

This interview question yielded five domains: Deemphasized individuality, General maturation, Equanimity, Help takes many forms, and Miscellaneous.

**Domain 1: Deemphasized individuality (n = 12)**

Many participants shared that their sense of *meaning* has changed over time as they have come to recognize their personal limitations and/or appreciate contexts beyond themselves. There are two categories.

**Category 1: Increased humility (n = 7).** Some counselors described how they have become increasingly aware and respectful of their own limitations and have realized they are less driven by their own ego or desire for success.

*You come out of school and you're full of knowledge and training, and you think you're just going to go out there and just be saving people left and right. And change the world! But then you spend ten years in the trenches and realize that you can't help everybody ... I mean you think that everyone's going to be excited to hear what you have to say because you're excited about it. (Laugh) ... And I think ... your sense of place in the universe becomes a little bit more realistic [over time] ... You don't necessarily think that for the rest of their lives they're going to look back and thank you every day. That's not the type of job we're in.*

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*Before, in order for me to feel like I helped a patient, I would need to see them walking away happy, if you will, or walking away liking me ... It would make me feel that I helped them and therefore I would get meaning.*

*Whereas now, I don't need the patient to like me in order for me to know that I've helped them and to know that I've had a positive influence.*

**Category 2: Increased recognition of the value of relationships (n = 6).** A few counselors expressed that they have become increasingly aware, and appreciative, of interpersonal connections with others.

*I think what's happened over the years is that, after I understood the genetics, then [I became] kind of fascinated with the patients' stories. And more about what they know and what I can learn from them in terms of their own life experiences ... more than what I can tell them about that stupid gene!*

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*I like being able to ask families how their other kids are doing or how graduation was or things like that. When I first started, it was primarily seeing patients one time and going over test results and that was just kind of it. So, I like the human aspects of my job now, and I think that's definitely different than when I started.*

**Domain 2: General maturation (n = 10)**

A number of individuals identified the importance of simply maturing over time as having an important influence on their evolving sense of *meaning*. It should be noted that this domain was initially created for more general responses from participants about simply feeling “older and wiser” over time, so a number of the responses are relatively generic in nature.

*I think it's also potentially just a little bit of maturity, too. You know, where the longer you're doing this, the older you're getting. And just having a better understanding of people and life and how it works ... and the complexities of life ... And I think that maturity helps you to see the bigger picture.*

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*I think there are things that have changed mostly because your views change the longer you live and the more you see ... God, how naïve I was! You know, I think that the things that have happened in my personal life have made me a better counselor, too. Having just more life happen to you. The more you understand how much people have been through, [the more] you also understand how impactful certain things are.*

### **Domain 3: Equanimity (n = 8)**

Several participants described how they have developed an increasing mental calmness over time as a direct result of difficult and/or complicated patient contexts.

*I allow myself to think that it's okay that there are a lot of things that I don't understand, and I don't feel like I have to understand ... So, I am kind of okay with the uncertainty and the not feeling like I have to know everything and ... I haven't needed to challenge everything.*

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*The things that have changed are partly my ability to go with the flow and to not be shocked and not be surprised.*

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*You do what you can do and that release [was] so hard ... that ongoing struggle of needing to release responsibility. Like, I've done what I can do. I didn't succeed. But I have to let that go. They aren't at a point where they can be ready to let me help them. So, I have to just stop. And it's that sense [now] that there is that stop; that there is a point when you need to let it go [and that is meaningful].*

**Domain 4: Help takes many forms (n = 6)**

Some counselors emphasized how they have come to learn over time that genetic counseling is more than just giving information or providing support; that different people may indeed have different needs.

*... the different ways I can have impact on individuals have changed. They've become broader ... through personal loss and exploring that avenue in patients' eyes. Or through difficulties in their financial circumstances where you just listen more and provide more resources for them. I think my attempts to continue to help are still there, I just see broader options.*

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*... as an individual, I can impact more people than I know. Just one of my actions, one thing I say, one action I take, may clearly or obviously influence whoever's the object of my conversation or action ... [I now] just acknowledge that my place, while small ... could have influences that [we'll] never know about.*

**Domain 5: Miscellaneous ( $n = 5$ )**

Five responses could not otherwise be classified. For example, a few individuals remarked on losing energy and/or emotional tolerance for their difficult jobs. A few also commented that their sense of *meaning* has not changed. Of note, a number of participants first said their sense of *meaning* had not changed over time but then went on to provide examples that did actually reflect some sort of change. In those cases, their described changes were coded in the above domains within this section.

*... it becomes more important for me to remember the reasons that I'm doing this, because of the deeper meaning in it. And I guess that, it's not that it's more important, it's just that when you're at a new job, everything is new and exciting ... Relying on the deeper meaning of the job becomes more important to keep yourself happy and keep yourself sane.*

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*As a genetic counselor, I started to feel a need to move away from the direct patient care ... I think for me mentally [and] emotionally, I can feel myself move away from the day-to-day, face-to-face care.*

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*In general, I would say that most aspects have not changed because I got into the profession as a more mature adult.*

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*I feel like I've gotten a lot more cynical about business and people in business ... I think, especially, that changed for me when I saw what was out in the big bad world ... I'm feeling like I've just gotten more cynical.*

*The things that my mom used to tell me that I would get mad at her for, because I used to say, “Why are you so pessimistic?” Now, I find myself saying those things! (Laugh)*

### **Summary of Responses Related to Changes in *Meaning* over Time**

A few important themes emerged from participants’ considerations of how their views on *meaning* have shifted over time, especially as inspired by contexts within their genetic counseling practice. Approximately half spoke of how they feel they have become less “self-focused” through their work. For some, this has been experienced through a direct increase in humility, either through working with patients who live with much greater challenges than they have ever experienced or in recognizing the limitations to their own book knowledge from their graduate training. For others, their sense of *meaning* has shifted through an enhanced appreciation for the value of relationships (i.e., beyond focusing on the science alone or the idea that providing a diagnosis is curative). Some participants described simply feeling as if they have matured over the years and that they have a better understanding of how life works. More often than not, however, participant responses within the maturation domain were a bit vague in nature. And finally, some counselors expressed a belief that they have strengthened in their abilities to remain mentally calm during stressful situations and recognize that their help can take many different forms. Overall, it seems the participants gained increasing awareness both of their own limitations and also the extent of their helping potential.

### **Reasons for Participating in this Study**

**(Interview Question 8: What, if anything, prompted your decision to participate in this study?)**

This interview question yielded responses classified within four domains: Interest in the topic, Importance of self-reflection, Paying the research experience forward, and Desire for voice (or issue) be heard.

**Domain 1: Interest in the topic ( $n = 15$ )**

Over half of the participants expressed generally being intrigued by the topic. A number specifically commented that it was a unique research question compared to previous genetic counseling studies to which they had been exposed.

*[This] came over the listserv, and I thought that your question was amazing! Because with the transitions that I've been going through in the last few years, that's what I've been asking myself. "What is meaningful? What in my life is important stuff? What is the core? What are the principles?" So, to see that reflected in your question, I think appealed to me.*

**Domain 2: Importance of self-reflection ( $n = 11$ )**

Many counselors indicated it felt beneficial to take time out to reflect on their experiences, for the purpose of increased insight and/or self-awareness. A number also noted that it was specifically helpful for them to speak with a neutral/anonymous third party to promote insight rather than the defensiveness they often experience with these topics when talking with friends or family members.

*I don't always say 'Yes' to a follow-up interview ... [but] I've needed to find more personal meaning in my work than I anticipated when I started ... I think this kind of interview can help me clarify my thoughts on things by having someone ask specific questions.*

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*More self-reflection [is why I participated]. These types of things definitely come up when I speak with my family, but it's harder to be completely frank with someone else than it is to just be frank with yourself [or when] speaking under the pseudo-anonymity of this project. You're a neutral sounding board for me, to be able to express [myself], and you [helped] me with your reframing, to get me to reconsider things and to clarify things from my own life.*

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*This was an opportunity where we were asked about our thoughts and feelings, which is kind of a shift. And so I appreciated that. And also, this is one of the few days that I have a couple hours for myself, because my boys are at a summer camp. [So], what's more meaningful? Cleaning up the house and going grocery shopping? Or talking about a study on meaning? It's obviously the study on meaning! (Laugh)*

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*Thank you very much for prompting this self-reflection. I feel like I kind of got a therapy session for free! (Laugh)*

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### **Domain 3: Paying the research experience forward (n = 9)**

Several counselors spoke directly to wanting to contribute to the research process, specifically because they had completed their own similar studies in the past and wanted to be helpful to the researcher.

*I remember being a student and trying to get opinions. And there's always that aspect of, "Am I going to get enough responses?!"*

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*I've only been out for about three years, and I know what it's like to do a research study and to try and get people to help.*

**Domain 4: Desire that voice/issue be heard (n = 4)**

A few individuals shared that their motivation to participate was partially related to having a unique perspective and wanting that perspective to be represented. Three of these four participants mentioned wanting to share their unique religious perspective in a field that is often viewed as non-religious.

*I did think my journey and my coming into this profession as a more middle-aged person might be interesting in your study; because most of my colleagues are much younger and maybe haven't had children. I mean, maybe they are very self-aware, and I was just late to the game. (Laugh) But I thought ... maybe if I take the time to think about this and share my story, that it might be an important contributor to your study.*

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*I'm somewhat of a minority in the profession of genetic counseling as a Christian ... And to have experienced that really for the first time as an adult was somewhat shocking. So, whenever I see studies regarding life's meaning or coping strategies or more of the psychosocial sides of life, I tend to participate because I do want to try and help raise awareness that people who are both Christian and genetic counselors at the same time,*

*that we're not doing a disservice to [the] families, and that we are furthering the field. And that we are good at what we do.*

### **Summary of Responses Related to Reasons for Participating in this Study**

Participants seemed to present rather straightforward reasons for choosing to participate in this study. The majority provided short responses about how the topic seemed generally interesting, but a few of those emphasized how unique it seemed compared to some of the other studies they are invited to participate in through the NSGC email listserv. Almost half of the participants described an intention to engage in more thoughtful self-reflection regarding their own sense of *meaning* and values than they are accustomed to (or feel as if they are able to do with friends, family members or coworkers). A number of individuals stated their reason for participating was based in empathy for having completed similar studies for their own graduate training and wanting to help the research process. Finally, a handful of counselors emphasized that they chose to participate primarily because they wanted their perspective on a specific issue (related to their own religious identification, parental status, or non-traditional experiences) to be heard in the field.

### **Thematic Differences within Participant Responses**

As described earlier in this chapter, no strong thematic differences across the major research questions due to counselor demographics were found. For example, no significant differences were noted between participant responses based on their genetic counseling sub-specialty areas. Nevertheless, the data analysis team did note a few obvious differences between participant groups. For

example, those participants in a committed relationship tended to identify their partners as important sources of *meaning* and parents similarly identified their children. A few nuanced differences based on demographic variables such as gender, ethnicity and years of experience were also noted, although these differences remain largely speculative due to the small numbers of individuals in certain demographic groups.

For example, only three males participated in the interview for this study. These three males tended to have shorter, less detailed answers to questions and required a bit more prompting and/or clarification from the interviewer to keep the conversation going. Similarly, they seemed to provide less emotional content to their responses, although one stated that genetic counseling has been enjoyable because it has “opened a window to feelings” that he didn’t think he had before. The three males also stated that their overall views on *meaning* have changed minimally since beginning work as a genetic counselor (although it should be noted that all three had worked less than five years in the field).

There were also only four participants who identified as an ethnicity other than White/Caucasian. No major differences were seen comparing their individual responses to the other participants. However, a few of these participants did go out of their way to identify their cultural background as an important source of *meaning*. For example, one participant said, “[I have] gratitude for my roots and that has an influence on who I like to help. That’s not to say I don’t like to help other groups. I simply have more enjoyment when working with patients from my shared cultural background.” Also, none of these participants noted a specific

religious identification as important to their sense of *meaning*. One participant went out of her way to say, “I don’t think of [*meaning*] as a religious thing. I think of it as a family thing and a cultural thing, more so than religious, spiritual, or anything like that.”

And finally, only five participants assigned to the “Seasoned” category (i.e., having more than 15 years of genetic counseling experience) were included in the analysis. No major differences were seen comparing their individual responses to the other participants. However, a few of these participants did go out of their way to speak to feeling more confident and comfortable with their own belief systems as compared to when they were younger and/or just entering the field. They also tended to speak to an enhanced ability to work through value conflicts with patients due to increased humility (e.g., “My goals are much more modest [now] ... I would like to be able to make a difference in the lives of some people. And I know there are still some families who I’m not able make a dent with”), increased equanimity (e.g., “The things that have changed [in the past 17 years] are my ability to go with the flow, not be shocked, and not be surprised”), and enhanced empathy (e.g., “With 20 years of experience under my belt, I just welcome [other people’s perspectives] so much more than I did”).

## Chapter 5

### Discussion

*All want to sleep at night in contentment, and in the peace of knowing one has responded to the need—the call—of others; to ease their pain, give comfort, and instill a sense of hope.*

*(Abrams & Kessler, 2002, p. 16)*

Previous efforts have been made to empirically investigate genetic counselors' beliefs and values in order to better understand the interplay between their personal attributes (Pirzadeh, McCarthy Veach, Bartels, Kao & LeRoy, 2007), professional lessons learned on the job (Runyon, Zahm, McCarthy Veach, MacFarlane & LeRoy, 2010), and professional practice (Bower, McCarthy Veach, Bartels, & LeRoy., 2002; McCarthy Veach, Bartels & LeRoy, 2001). Genetic counselors' personal beliefs and values have also been identified through individual interviews, case studies, and essays, in an attempt to develop a deeper understanding of these phenomena in narrative retrospect. Yet, no empirical work has been done to establish a rich and comprehensive sense of the extent to which genetic counselors experience their own sense of *meaning* within their lives and how this sense has been shaped over time. Although one might postulate beliefs evolve over time as genetic counselors gain both professional and personal life experiences, the generalizability of such findings may be limited. More specifically, data are lacking about how genetic counselors develop their sense of *meaning* prior to working within the field and how they both experience and express this *meaning* throughout their work. Consequently, additional research is needed to further understand the potential synergy between personal beliefs and professional practice.

Accordingly, the present study was a qualitative investigation of genetic counselors' views of their sense of *meaning* over time. There were four major research

questions: (1) How do genetic counselors define a meaningful life for themselves; (2) What specific influences have shaped this sense of *meaning* over time; 3) How do they experience *meaning* within both personal and professional contexts; and (4) What are some particular genetic counseling cases that have challenged and/or reaffirmed their personal views on *meaning*? Analysis of responses to these questions was intended to help elucidate the potentially transformative nature of personal and professional lessons on genetic counselors' sense of *meaning*, how these lessons interface with their clinical practice, and provide further avenues for genetic counseling research and training.

A total of 68 genetic counselors engaged in a semi-structured, telephone interview, and 25 of these interviews were analyzed with a modified version of Consensual Qualitative Research (CQR; Hill, Thompson & Nutt-Williams, 1997; Hill et al., 2005; Hill, 2012) to extract broad themes, domains and categories from participant responses. The following sections contain a summary of major findings, a discussion of the findings in connection to previous research, study strengths and limitations, training and practice implications and recommendations for future research.

### **Summary of Major Findings**

Detailed results for this study are presented in Chapter 4. A specific list of domains and categories that emerged from the broad research questions can be found in Table 3. Following is a discussion of major findings extracted from participants' responses.

Every interview began with the primary investigator reading a brief introduction: "The purpose of this study is to explore issues and questions of *meaning* experienced by genetic counselors and to examine how they personally manage these issues and

questions. Everyone has ways of making sense of things that happen to them and others. I am interested in how you do this for yourself, especially as it relates to your experiences as a genetic counselor over time. For this study, participants are encouraged to think about what makes their lives feel important to them, which may or may not include things such as relationships, work, leisure and values. In addition, participants are encouraged to consider the term *meaning* within the broad scope of any religious, spiritual, existential, philosophical, or ecological realms to which they may relate.”

### **General Definitions of a Meaningful Life**

Participants were first asked to define a meaningful life for themselves, including any particular beliefs, values or activities that help provide them with that sense of *meaning*. Responses to this broad question were quite diverse in scope ranging from individual pursuits of achievement and reaching potential, to social contexts such as human connectedness and striving to make the world a better place for others. The genetic counselors appeared to strongly value interpersonal connections. For instance, they experienced a deep sense of *meaning* when they feel they are able to be emotionally present for another person and/or are generally helpful to someone in need. Most participants spoke of their family and friend relationships as being the most important things in their lives; moreover, providing service to loved ones at home affords them a great sense of fulfillment and satisfaction. Others spoke in more global terms of helping others by improving the world around them, not only for themselves, but for everyone.

One method several individuals identified for monitoring their pursuits of *meaning* was reflecting on these questions: What might others say about me at the end of

my life? What might I be remembered for? For being kind, compassionate and selfless? Or for how much money I made and what types of positions I held? They seemed to strongly prefer being remembered for their selfless nature; this preference has helped motivate their daily decisions.

It makes sense that the two most important aspects of a meaningful life were satisfying relationships and helping others. Genetic counseling is a helping profession that allows individual practitioners to make real differences in people's lives. While this connection may appear obvious (and will be discussed in greater detail within the context of their specific practice), the enthusiasm with which many participants stated their value for relationships is noteworthy. In this sense, it is crucial that genetic counselors remain connected with coworkers, clinical teams and patients so as not to contribute to loneliness and compassion fatigue. It would be a mistake to assume that genetic counselors' sense of *meaning* within their work comes exclusively from relational experiences and subsequent ability to help patients. This study's findings also serve as a reminder for the sometimes equally strong individual drives of achievement, gaining knowledge, utilizing one's unique gifts, reaching individual potential, personal hobbies and general well-being.

### **Sources and/or Influences on One's Sense of *Meaning***

Participants were also asked to identify various sources throughout their lives that have helped shape their definition of *meaning* over time (i.e., important people, events, and contexts). Of note, there was definite overlap in responses between how participants defined a meaningful life for themselves and what they identified as historical sources of influence on their definitions. By far the most prevalent influences were

“Health/illness/loss” and “Religious/spiritual contexts.” Their prevalence likely was due to specific interview prompts regarding these potential areas of influence. Nevertheless, the emotional impact of these specific contexts for some participants offers preliminary evidence of their significance.

Participants provided numerous examples of how their own personal health struggles have dramatically impacted their sense of *meaning*, often in the form of increased empathy for others. Similarly, a number of individuals noted how witnessing others’ health concerns (i.e., in family members, friends and patients) has changed the way they view health, purpose and *meaning*. A handful of counselors did share that they had not experienced or witnessed much loss in their lives. Although this may simply represent the idiosyncratic nature of loss, even these individuals referenced their lack of health issues as an inspiration for their sense of *meaning* over time, often in the form of increased gratitude or appreciation.

With respect to religious/spiritual contexts, some participants described unpleasant experiences, which contributed to their denouncing or moving away from formal religious practice altogether. Some also noted moving away from religious practice over time but finding a deeper sense of *meaning* within broader spiritual beliefs and practices. Of note, over half of the interviewees described embracing their formal religious backgrounds and/or current practice as central to their overall sense of *meaning* and purpose, and they unanimously expressed that these were positive experiences. These findings are fairly consistent with a previous study that found the majority of genetic counselors describe themselves as moderately to highly spiritual and identify with religious affiliations as frequently as the general U.S. public, but are also “significantly

less likely to believe in god, attend religious services, pray and believe in an afterlife” (Cragun, Wotanski, Myers & Cragun, 2009, p. 551). Also noteworthy, a few religiously-affiliated participants in the present study expressed some frustration about what they perceived as a pervasive assumption within and outside of the field that genetic counselors are anti-religious.

Again, the genetic counselors in this study spoke frequently of the importance of personal relationships not only within their general definition of *meaning*, but as significant sources of influence on that definition over time. They provided examples of respected family members sharing life-changing wisdom/advice throughout their lives, friends offering emotional support during difficult times, and broader cultural groups passing down collective beliefs and values through the generations. Participants also spoke very highly of their professional relationships as important sources of influence on their definitions of *meaning*, including trusted colleagues, inspirational mentors/supervisors and memorable patients.

Some participants noted specific personal values (e.g., honesty, openness, integrity and gratitude) have provided an underlying foundation on which to attach their experiences and foster a sense of *meaning* over time. A few also expressed that their unique sense of *meaning* was likely based in part on their unique, inherent traits and characteristics.

Overall, although a number of participants appeared to rely on the provided interview prompts when asked about potential sources of influence on their definition of *meaning*, this was frequently the portion of the interview in which individuals became noticeably emotional and increasingly self-reflective in their responses. It seems that

asking genetic counselors to reflect on important sources of *meaning* has the potential to elicit deep reflection, insight and sometimes strong emotions. Some participants laughed, some cried; a number also directly thanked this investigator for providing an opportunity to share their historical experiences because it helped them recall memorable interactions with loved ones and contextualize some of their current motivations. These findings suggest the importance of creating opportunities for genetic counselors to reconnect with their personal histories as a means to help identify underlying values, internal motivations and personal styles; all of which have the potential to influence (directly or indirectly; positively or negatively) their clinical work.

### **Specific Contexts of *Meaning* Experienced within Genetic Counseling Practice**

When asked to reflect on the nature of their clinical work as genetic counselors, virtually all of the participants emphasized opportunities to help patients as the primary context that allows them to experience a deep sense of *meaning*. A number of counselors spoke of feeling blessed to have the opportunity to work in a field that offers such intimate human connection, along with continual opportunities to help patients in need. In this regard, the majority identified personally meaningful contexts in which they can offer emotional support to patients (e.g., through listening, supporting, caring), and those in which they can educate their patients by imparting information (e.g., regarding biology, testing protocols and risk management). Most described experiencing *meaning* within their work when they are able to balance support and education and thereby contribute to patient empowerment. Some counselors also emphasized the invigorating intellectual challenge of mastering a complicated science and tailoring counseling based on unique patient needs, rather than striving to establish a one-size-fits-all approach.

It was common to hear from participants that exposure to the resiliency patients and families demonstrate in the face of illness and adversity significantly contributes to their own personal sense of *meaning*, most often by strengthening their own empathy. Participants also spoke of how patient experiences often vicariously spark their own internal self-reflection about how they might deal with similar health situations. Of note, some counselors also expressed that a sense of *meaning* feels most present (and/or fulfilling) when they receive direct expressions of gratitude from their patients, which allows them to feel successful and validated in their initial intentions to help others. Similarly, some of these counselors described past experiences of self-doubt or frustration when they have not felt patients appreciated their efforts.

These findings also suggest genetic counselors experience a great deal of *meaning* from their clinical work, and while this comes in a variety of forms, most revolve around their core motivation to help others in need. “Help” may be delivered in the form of educating a patient with disease-specific information or by providing a listening ear. And while it is possible the genetic counselors who volunteered to participate in this study did so based on their desire to share their positive (rather than negative) experiences, the findings suggest the profession of genetic counseling provides a diverse array of contexts in which individuals can experience, strengthen and express a personal sense of *meaning* in their work.

### **Specific Challenges to One’s *Meaning* Experienced within Genetic Counseling Practice**

Fewer domains emerged when participants were asked to provide examples of specific challenges to their sense of *meaning* experienced within their clinical work.

Again, this might be partially due to participant self-selection (i.e., those individuals were more motivated to discuss the positive aspects of their jobs rather than the challenges). Nevertheless, a majority identified value conflicts as a major source of challenge to their experience of *meaning*. This is congruent with the findings of Bower and colleagues (2002) who found value conflicts as a highly prevalent challenge for genetic counselors who rated the frequency of various ethical/professional challenges within their work. As an example, a number of participants in the current investigation expressed that it can be especially challenging to work in prenatal settings when they disagree with patients' reasons for terminations, or conversely, for continuing a pregnancy.

Additional prevalent challenges to *meaning* centered on genetic counselors' general discomfort with the pain, loss or suffering of patients and their families. A number of participants voiced how, although quite difficult, they have learned to accept that life is not fair and that bad things happen, even to good people. While some appeared to have reconciled with this reality, others expressed a greater degree of helplessness and, in a few cases, hopelessness, in their perceived inability to serve others in their time of need (i.e., similar to a sense of compassion fatigue as described earlier in this paper). Relatedly, some counselors provided examples of competing obligations within their daily work (e.g., insurance pressures vs. individual patient needs, and long hours at work pulling them away from their families), as well as limited resources within the field (e.g., perceived low financial compensation) as specific challenges to their views on *meaning*.

Of note, one interview prompt provided to every participant was how they worked to resolve such challenges to their sense of *meaning* within their clinical practice. No additional thematic domains were identified as the resolutions were specific to the

challenge each participant described. For example, when faced with a value conflict, participants tended to resolve it by reminding themselves to appreciate individual differences in their patients, strengthen their own sense/skill of empathy, and work to support the patient's autonomy whether or not they agree with their decisions. Consequently, such responses were coded as each of the respective domains/categories within the section: "Specific Contexts of *Meaning* Experienced within Genetic Counseling Practice." Nonetheless, these findings also indicate genetic counselors often are able to draw upon coping strategies for emotionally challenging patient contexts while reflecting on their own personal sense of *meaning* as it is defined within their work. Of course, in the moment of ethical or professional challenges, this can be difficult to do without the help of consultation, supervision or peer-support (cf. Bower et al., 2002).

### **Changes in *Meaning* over Time**

A few important themes emerged when participants considered how their views on *meaning* have shifted over time, especially as inspired by contexts within their practice. A common response (for approximately half of the participants) was feeling they have become less "self-focused" through their work. Some counselors described increased humility that came about either through working with patients who live with much greater challenges than they have ever experienced or in recognizing the limitations to their graduate preparation. For others, their sense of *meaning* has shifted through an enhanced appreciation for the value of relationships as opposed to an exclusive focus on the science or the technical aspects of the work. Some participants also described feeling as if they have simply matured over the years and thus have a better understanding of the nuances of life. Finally, some counselors expressed a belief that they have strengthened

in their abilities to remain mentally calm during stressful situations and recognize their help can take many different forms. Such descriptions of increased humility, strengthened appreciation of ambiguity, and strengthened emotional awareness over time are strongly congruent with extant research on genetic counselor professional development (Miranda, 2012; Zahm, 2009) as well as on counselors/psychotherapists (Orlinsky et al., 2005; Ronnestad & Skovholt, 2003). Overall, it seems the counselors gained increased awareness of their limitations as well as the extent of their helping potential.

As the present investigation did not involve quantitative analysis beyond frequencies for basic demographic information, it was difficult to assess thematic differences in the extent of change in one's views on *meaning* based on age or years of experience. As for age, work-specific experience effects may indeed overshadow potential age effects. Findings regarding expertise in genetic counseling (Miranda, 2012) and in counseling/psychotherapy (Jennings & Skovholt, 1999) suggest the longer clinicians practice, the more they tend to commit themselves to life-long learning, consistently call upon personal experiences to inform clinical practice, develop an appreciation of ambiguity inherent to their nuanced work, and become increasingly emotionally-receptive and self-aware. Research findings have also shown, however, that years of experience alone do not account for the variation in reaching professional developmental milestones (Orlinsky et al., 2005; Ronnestad & Skovholt, 2003) or expertise (Jennings & Skovholt, 1999).

The participants' responses to the earlier interview questions (i.e., how they define a sense of *meaning* and sources of influence for that *meaning*) suggest the particular qualities of empathy, equanimity, and tolerance for ambiguity noted herein are

characteristics nurtured in someone long before practicing as a genetic counselor, even if they are only realized over time through one's work. In this sense, they may serve as some of the traits that motivate people to pursue genetic counseling as a profession and are only emboldened by one's work.

It also appears the interviewees generally considered changes in their definitions of *meaning* as positive shifts, reflecting increased humility, maturation, and openness, although a few individuals did note some disillusionment with their profession. The finding that some participants did express frustration and/or disillusionment for their practice, suggests the importance of providing education and practice around self-reflection, tolerance and acceptance early in one's training, as well as throughout their careers, in order to help mitigate risk for compassion fatigue and burnout from this challenging work.

### **Reasons for Participating in the Study**

Four thematic domains reflect interviewees' expressed reasons for participating in this study. While the majority simply stated that it is a generally intriguing topic, others said they wanted to pay the research experience forward (i.e., as many of them engaged in similar studies as part of their own graduate training, they wanted to be helpful out of a sense of empathy). Particularly noteworthy, almost half explicitly stated that they chose to participate because it was an opportunity to engage in self-reflection regarding their current work with a neutral third party. These individuals also expressed that they often become defensive when attempting to engage in similar *meaning*-based conversations with coworkers, family members and friends. These results suggest genetic counselors are genuinely interested in opportunities to engage in self-reflection. Four individuals

shared that their motivation to participate was partially related to having a unique perspective that they wanted to be represented in the findings. Three of these counselors wanted to share their religious perspective in a field that they feel is often viewed as non-religious.

### **Connection of the Findings to Theory and Prior Research**

As described throughout this paper, previous efforts have been made to empirically investigate genetic counselors' beliefs and values in order to better understand the interplay between their personal attributes and professional practice, although those findings have been based on genetic counselors' beliefs and values at one point in time. The following section revisits extant literature reviewed earlier in this paper (both within and beyond the field of genetic counseling) to help interpret results of the current study regarding themes that emerged from genetic counselors' experiences of *meaning* over time.

### **An Existential Foundation**

In Chapter 2, this investigator briefly reviewed two historical efforts to apply an existential framework to therapeutic work with clients (Frankl, 1984; Yalom, 1980, 2002, 2008). The intent was to provide readers with a framework for understanding the substantive connections made by participants when asked the broad question: *How do you define a meaningful life for yourself?* In his 1959 memoir entitled *Man's Search for Meaning*, Viktor Frankl provides deep and often disturbing descriptions of his experiences at World War II concentration camps, and subsequently argues that the journey to discover a true sense of *meaning* (even in the most insufferable of contexts) serves as a human being's primary motivation in life. Frankl also suggests despair can

only begin to be mitigated through active self-reflection and a discovery of *meaning* in one's experience, and that profound *meaning* can be experienced in three important ways: "by creating a work or doing a deed; by experiencing something or encountering someone; and by the attitude we take toward unavoidable suffering" (Frankl, 1984, p. 133).

As existential theory suggests, participants did often call upon their personal and professional experiences of suffering as well as speak to the importance of introspection (and integration) of such experiences to help provide *meaning* to their lives. The majority seemed to retain a strongly positive tone throughout the interview. Nevertheless, they certainly shared numerous examples of suffering that have challenged them to work towards establishing a sense of *meaning* through active self-reflection. While personal health issues, as well as those experienced by friends, family members, and patients often reminded them of the frailty of life, most participants spoke more emphatically about the resilience they have observed, learned and experienced in the face of adversity. Consistent with Frankl's description, many also expressed that they can experience profound *meaning* by helping their patients through general support, education, empowerment and advocacy.

Irvin Yalom (1980; 2002; 2008), a more contemporary existential author and psychotherapist, similarly speaks about the unique and intimate nature of the therapeutic process and its integral connection to the construct of *meaning*. His widely cited four ultimate existential concerns of *death, freedom, isolation* and *meaninglessness* appear congruent with the major findings of the present study, although these exact terms were not used by the participants to describe their experience of *meaning*.

Some participants expressed awareness that their time on earth is finite, and, therefore, they feel motivated to make the best of their time by working to make the world a better place for everyone. A number of counselors said they sometimes envision what their friends and family members might say about them when they pass away, as a guiding principle for their daily behaviors. These results suggest genetic counselors do not simply face issues of *death* with their medical patients, they also sometimes confront (although often vicariously) their own sense of mortality within the nature of their work. Consequently, their work seems to serve as a catalyst for increased self-reflection, insight and enhanced sense of *meaning*.

Although no one explicitly described fear of *isolation* per se, their strong emphasis on the importance of individual relationships with family members, friends, colleagues and patients is congruent with Yalom's description of the ultimate existential truth of *isolation*. Satisfying connections with others were not only the most frequently identified context for a definition of a meaningful life, but it was a consistent theme throughout other domains and categories as well (e.g., sense of community, service to others, making the world better, helping others, human connection, and increased recognition of the value of relationships). Although Yalom suggests we all must eventually become concretely aware that we both enter and leave the world alone, it appears that without interpersonal connection throughout one's life, many genetic counselors feel their sense of personal *meaning* is left unfulfilled.

Yalom (2002) describes the practice of therapy as "a life of service in which we daily transcend our personal wishes and turn our gaze toward the needs and growth of the other" (p. 256). This perspective was especially evident in participants' descriptions of

how the *meaning* they draw from their clinical work occurs most frequently in contexts in which they can help others. Their help occurs through the provision of general support and information, both of which result in patient empowerment.

Also, as the concept of *meaning* served as the foundational context for the present investigation, Yalom's ultimate existential truth of *meaninglessness* (and one's responses to this antithetical existential "truth") is inherently implied in virtually all of the participant responses for this study. All participants were invited to note what was meaningful to them in their lives and their responses were diverse in nature and scope. Similar to Nietzsche's famous quote, "He who has a *why* to live for can bear with almost any *how*" (as quoted in Frankl, 1984, p. 126), many counselors also spoke to the deep sense of *meaning* they have garnered from difficult contexts. These contexts included illness experiences and loss (both personally experienced and indirectly witnessed in patients and loved ones). A number also noted their desire to engage with their own sense of *meaning* through guided self-reflection was a primary motivation to be in this study.

Yalom also notes that working as a therapist is not only a privilege to share in a patient's *meaning*-making but also that "[leaving] something of ourselves [as therapists], even beyond our knowing, offers a potent answer to those who claim that meaninglessness inevitably flows from one's finiteness and transiency (Yalom, 2008, p. 83). This sentiment is consistently demonstrated by participants who spoke to their enhanced experience of *meaning* when their practice moves beyond simply helping the other person (i.e., uni-directional) to also receiving their own benefits (i.e., bi-directional) through vicarious lessons, increased empathy, validation through gratitude, intellectual challenge and resiliency. These findings also seems to ring true with Yalom's emphasis

that one of the greatest benefits a therapist can encounter is learning from and being helped by clients: “We cannot say to them *you* and *your* problems ... we are, all of us, in this together” (Yalom, 1989, p. 14).

### **Professional Development and *Meaning***

Although the construct of *meaning* has not been explicitly examined in the genetic counseling literature until this study, it is commonly referenced (if not named directly) within the professional development literatures in counseling/psychotherapy and genetic counseling. Those literatures provide a useful foundation for considering how clinicians develop over time and they suggest various contexts in which practitioners develop and/or experience a personal sense of *meaning* within their work. Clinicians not only acquire specific skills and competencies throughout their careers, they also participate in meaningful interpersonal contexts with clients and coworkers, and engage in internal tasks such as clarifying their values and strengthening their own self-awareness (Elman, Illfelder-Kaye, & Robiner, 2005). In this regard, the present sample of genetic counselors spoke strongly about valuing the technical skills they develop over time, but they also emphasized these skills are not fully realized and/or appreciated without meaningful interpersonal interactions with patients, patient families and colleagues.

As for integrating one’s personal and professional selves over time (through reflection and resolution of personal beliefs, attitudes, preferences, values and skills), a number of authors have described this integration as an important, life-long, and often non-linear journey (Moss, Gibson & Dollarhide, 2014; Orlinsky et al., 2005; Skovholt & Ronnestad, 1992, 2003). In addition, committing oneself to life-long learning, consistently calling upon one’s personal experiences to inform clinical practice,

developing an appreciation of ambiguity inherent to their nuanced work, and becoming increasingly emotionally-receptive and self-aware, are integral components of professional development (Jennings & Skovholt, 1999). As one might expect, the present participants often described feeling more self-reflective and mature over time, even if they had not taken overt steps to clarify their values in the process. Nevertheless, a number of counselors also directly stated how much they appreciated the deliberate self-reflection required during their interview and expressed interest in having similar conversations with their colleagues and supervisors in the future. Personal experiences and personal characteristics such as regular self-reflection and a constant striving for self-improvement translate into levels of expertise to a greater extent than years working in a field (Jennings & Skovholt, 1999; Jennings, Goh, Skovholt, Hanson, & Banerjee-Stevens, 2003; Jennings, Sovereign, Bottorff, Mussell & Vye, 2005; Jennings et al., 2008; Skovholt & Jennings, 2004; Sullivan, Skovholt, & Jennings, 2004).

The professional development literature within the field of genetic counseling also provides a frame for understanding the findings of the present study. Zahm (2009) found genetic counselors consistently experience intense and profound lessons from their direct interactions with patients (often based on the patients' suffering and related resilience). She also found they call upon their personal lives to inform their work with patients (e.g., increased empathy), develop sophisticated ways to conceptually connect their individual experiences to pull *meaning* from them, and develop a strengthened/integrated sense of self over the course of their careers. In this regard, counselors in this study commonly identified poignant experiences with patients as often as personal experiences with family members and friends as informing their values and clinical work. Although this finding

might be due in part to the interviewer equally prompting reflection about both professional and personal contexts, it does suggest the importance of tending to both realms in order to best understand genetic counseling practice.

As part of an investigation into the development of expertise within the field of genetic counseling, Miranda (2012) also suggested that genetic counselors tend to have deep levels of curiosity and a value for life-long learning. Furthermore, she identified one sign of expertise within genetic counseling as authenticity within one's practice, as well as an ability to call upon one's personality style to help shape his or her counseling style with patients. The counselors within the present study certainly spoke strongly about the importance of intellectual stimulation and a quest for knowledge as driving forces in their work. Moreover, a number also described how their sense of *meaning* has strengthened as they have learned to integrate their own personal qualities with their professional skills, thereby providing authentic practice to patients in need.

### **Genetic Counseling Practice and Issues of *Meaning***

While exploring interpersonal, intrapersonal and professional lessons learned by genetic counselors since initiating clinical practice, Runyon et al. (2007) found genetic counselors tend to develop a synergistic relationship between their personal and professional experiences over time. They also find that they learn how to begin letting go of control (e.g., by managing one's values/biases/opinions, accepting others' viewpoints, and accepting that some matters are uncontrollable). Similar to Zahm (2010), these authors concluded counselor self-awareness, self-reflection and learning from others are "necessary catalysts" (p. 382) for insights to transfer to actual outcomes. In the present study, a number of participants spoke of the challenging nature of clinical contexts that

emphasize their lack of control, but also a strengthened sense of *meaning* when they have come to terms with letting go of that control over time.

Similarly, Pirzadeh and colleagues (2007) examined some of the personal beliefs and values commonly experienced by genetic counselors. They found genetic counselors strongly value benevolence and universalism, which seem to represent a self-transcendence (concern for others) value type. They concluded the apparent preference for a self-transcendent value over self-enhancement values seems to “support the basic tenets and goals of genetic counseling (e.g., respect for autonomy, interpersonal concern, empowerment of the individual, and a valuing of the practitioner-patient relationship)” (p. 770). While individual aspirations such as gaining knowledge, reaching potential and general contentment were certainly important motivations that surfaced in the present sample’s responses, the participants did most often come back to their deep motivations to help others, to be of service, and to make the world a better place while describing their experiences of *meaning*. Pirzadeh and colleagues also emphasized that when genetic counselors provide clinical service to patients, “who they are may play as important a role as what they know” (p. 763); arguing their personal values may indeed influence their presentation of facts and decision options to patients, as well as whether they invite patients to consider their own moral consequences related to their decisions. Similarly, a number of counselors in the present study described how important it is to not unduly influence their patients’ decision-making in any way, and that they have begun to realize the importance of reflecting on their own values and biases as a means to best support patient autonomy.

Finally, the present results seem to be congruent with McCarthy Veach and colleagues' (2002, 2012) "Defining Moments" essays. As part of that effort, a number of genetic counselors provided first-person narrative accounts of meaningful turning points in their careers and examples of catalysts that included honoring personal life events, listening, supporting patient autonomy, patient resilience, gratitude, hope, perseverance, self-reflection and balance/integration of self. In describing the essays collectively, McCarthy Veach and LeRoy (2012) argue self-reflection regarding important catalysts in one's professional development across the career life-span helps further strengthen genetic counselors' personal qualities and counseling skills of "empathy, authenticity, honesty, self-awareness, resiliency, compassion, connection, courage, and commitment" (p. 166). Many counselors in the present study named some of these same qualities (e.g., empathy, resiliency, and compassion) as integral to their development and experience of *meaning* within their practice. Furthermore, McCarthy Veach and LeRoy (2012) describe the power in clinicians' defining moments often coming from a "readiness to learn from their experience, ability to engage in honest and often painful self-reflection, and their efforts to generalize their learning to their 'personal' and 'professional' selves" (p. 163). Similarly, counselors in this study often spoke with great emotion about the effects both personal and professional contexts have had on their views of themselves as well as their motivations to become more advanced clinicians, and simply better people.

### **Study Strengths and Limitations**

**Strengths.** This study possesses several notable strengths. Although related literature in genetic counseling and the field of counseling/psychotherapy make indirect references to *meaning* based on analogy and/or extrapolation, this is the first study to

explicitly examine the construct of *meaning* as it is experienced by genetic counselors. Moreover, only one published prior study (Pirzadeh et al., 2007) inquired about genetic counselors' current, or recent, beliefs. The present investigation is the first study asking participants to reflect on how they define the construct of *meaning*, and to identify important sources of influence on their definitions, throughout their entire lifespan. Despite limitations of self-report data that include potential recall bias and hindsight, the findings of this study provide insight into genetic counselors' beliefs and values prior to entering the field, and how they have shifted in their experiences of *meaning* since initiating their careers.

The representativeness of the sample to genetic counselors in the U.S. represents another strength of the current study. Participants comprised a wide range of experience levels (1 to 33 years), genetic counseling sub-specialties, and geographic regions, thus allowing for some tentative conclusions regarding genetic counselors' experiences of *meaning* within their practice.

Finally, the telephone interview format is a particular strength of this study, not only to allow for a geographically diverse sample, but also due to the intimate nature of the interview itself. Open, genuine and candid participant responses are crucial within qualitative research (Colaizzi, 1978; McLeod, 2001) and in-person interviews (especially regarding important aspects of one's personal life and development experiences) might have failed to capture the level of candidness obtained with the pseudo-anonymity of a phone interview. Indeed, this investigator spoke with more than a few genetic counselors who laughed and cried over the phone, as well as a few who noted that they had never before shared these personal experiences with anyone in their professional lives.

**Limitations.** A number of study limitations suggest caution when interpreting the results. First, qualitative research findings are not intended to be generalized to the population of interest. The purpose of qualitative inquiry is more generally concerned with generating rich, descriptive data for the purpose of establishing deeper understanding, stimulating discussion, and generating hypotheses for future research. Conclusions drawn from qualitative data, therefore, remain speculative and they require validation in subsequent investigations.

Another possible limitation concerns the interview questions, as they were quite abstract (i.e., providing a coherent and cohesive response to a stranger who asks for a definition of a meaningful life is a challenging task indeed). In this regard, a number of interviewees in this study mentioned how difficult this process was, and they experienced the broad nature of the questions, with minimal prompts, as somewhat confusing. This investigator attempted to predict and mitigate potential confusion by emailing the interview questions to participants a few days prior to the interviews. It did seem, however, as if several of the participants did not preview the interview questions, while others seemed to over-prepare by writing down concise answers and reading them during parts of the interview. Consequently, some of the creativity and spontaneity in the latter group of participants' responses may have been stunted due to this approach. Future studies should include more structured and/or scripted prompts to make interview questions more accessible and comprehensible for participants. Also, providing less time for participants to prepare scripted replies may inspire more organic and spontaneous responses.

This investigator conducted every interview, and while this might comprise a study strength (i.e., resulting in less variability in interview approaches and more consistency in responding to participant questions), it might also be a limitation. The use of a single interviewer risks the individual forming certain assumptions that unduly influence subsequent interviews.

Finally, although the demographics for the interviewed and analyzed participants appear largely congruent with published demographics for the population of genetic counselors, very few participants self-identified as males and non-White/Caucasian. Of note, the few non-White participants in this study were also those who described their broader cultural background as a strong influence on their personal beliefs and values. Greater inclusion of the voices of underrepresented groups of genetic counselors, therefore, is important to deepen understanding of the construct of *meaning*.

Also, it is unknown whether participants in this study differed from non-participants in one or more salient ways. As mentioned previously, perhaps participants were highly motivated and self-reflective individuals. In this regard, it is certainly plausible that some genetic counselors declined the invitation to participate due to either feeling negative in their current position, not wanting to share their experiences with others, or not placing much importance on the practice of self-reflection.

### **Practice and Training Implications**

The present findings help to illuminate some of the most subjective, and often difficult to articulate, nuances inherent to the life and work of a genetic counselor. While many experiences of *meaning* will remain as private experiences for individual genetic counselors, the results suggest the importance of individuals embracing these experiences

in ways that support their personal aspirations, enhance clinical work, and ultimately support the general tenets of the profession. Consequently, the findings have several implications for practice, especially for strengthening genetic counselors' experiences of *meaning*.

First, a number of the participants thanked this investigator for conducting the study and for engaging with them in a discussion based in the deep, heartfelt experiences they so often hold to themselves. Several genetic counselors said they had not yet had (or taken) an opportunity to share some of their personal beliefs and values with others in their field. These results not only emphasize the importance of creating accepting genetic counseling environments for patients and their families, but also the need to create venues for genetic counselors to process personal attributes as they relate to their work, so that they do not feel unnecessarily pressured to maintain false appearances with patients and colleagues.

Moreover, these counselors consistently reported appreciating the connections they made over the course of the interview between events in their personal lives and their clinical work. These findings suggest the importance of exploring the intersection between one's personal and professional lives on a routine basis. A possible venue for these conversations is personal therapy. Within this context, individuals often feel they can explore their inner thoughts, feelings, motivations and mistakes with a neutral third party (i.e., therapist) without fear of judgment, evaluation or discipline. The decision to pursue therapy, however, is a personal one. A more common and established venue within genetic counseling is clinical supervision.

At the training program level, clinical supervision offers students a setting in which to experience and engage with *meaning* in their practice. The current findings suggest supervisors could foster this activity by inquiring about the ways in which supervisees define a sense of *meaning* and how this construct has been shaped over time for them. In this manner, supervisors and supervisees can become increasingly aware of the types of clinical contexts (e.g., with patients, coworkers, and the profession as a whole) that inspire a sense of *meaning*, so appropriate action can be taken to best support student supervisee development. For example, if a student is faced with a specific value conflict while working with a patient, it can be especially helpful to explore this context within supervision to separate the student counselor's definition/experience of *meaning* from that of the patient's. In addition, exploration of issues of *meaning* within the context of supervision can help genetic counseling students identify parallel processes between their own personal life experiences and the experiences of their patients, as well as provide an opportunity to identify and reduce assumptions about patients having identical experiences. Of course, a clinical supervisor must be aware of the fine line between clinical supervision and personal counseling, and encourage supervisees to seek out counseling if these explorations trigger particularly challenging emotions and/or potentially detract from patient care.

Similarly, a number of participants emphasized how important their genetic counseling colleagues were to their experience and expression of *meaning*. While these findings indicate the importance of general team cohesion and morale, they also help to support peer supervision as a context in which to explore and process issues of *meaning* as they arise in one's clinical work. Middleton and colleagues (2007) and Zahm and

colleagues (Zahm, McCarthy Veach, & LeRoy, 2008) describe the benefits of peer supervision as exploration into challenging clinical contexts, receiving support and advice from trusted peers, and generally meeting the psychosocial needs of genetic counselors.

The results of the current study also suggest the importance of educators articulating the benefits of self-reflective practice at the outset of a student's graduate-level training, encouraging ongoing exploration into one's views on *meaning*, and inviting students into discussions regarding how they may experience and manage challenges to their views on *meaning* within their clinical work. While directly asking students to define their own personal sense of *meaning* may indeed result in thoughtful and engaging responses (as it did with participants within this study), students may also benefit from specific clinical vignettes that stimulate discussions regarding how they might identify and navigate their own personal sense of *meaning* while working with patients, coworkers and supervisors. In this regard, clinical vignettes potentially provide more effective training for the real-world situations not often presented in educational and/or training materials (Bower et al., 2002).

These suggestions are consistent with Zahm's (2009, 2010) emphasis on self-reflection exercises, classroom discussions and role plays to promote professional development. More specifically, Zahm suggests exposing genetic counseling students to common professional development trajectories can help them find ways to integrate their meaningful experiences with patients into their ongoing work, understand that their personal life experiences can strongly influence their professional experiences, and appreciate that professional development fluctuates over time and further concretized

through an ongoing commitment to self-reflection. Thus, it seems critical that genetic counselors in training have experiences with professors, advisers and supervisors that help model the process and benefits of considering contexts of *meaning*.

The findings also suggest the importance of opportunities for both students and post-degree genetic counselors to engage in focused reflection upon issues of *meaning*. This type of self-reflection might mitigate risk for burnout, help counselors cope with compassion fatigue, strengthen career satisfaction, and ultimately enhance genetic counseling service provision.

### **Research Recommendations**

Additional research is needed to further understand the experiences of *meaning* within the practice of genetic counseling. Researchers should make specific efforts to recruit more males and non-Caucasian genetic counselors. Although the present sample size (68 completed interviews; 25 coded/analyzed interviews) is a large sample for a qualitative study, subsequent quantitative investigations could help ascertain the extent to which the findings are generalizable to the broad field of genetic counseling practice. There are a few published questionnaires that could yield additional data with larger samples: The Meaning in Life Questionnaire (Steger, Frazier, Oishi & Kaler, 2006), The Existential Meaning Scale (Lyon & Younger, 2005), and The Spiritual Meaning Scale (Mascaro, Rosen & Morey, 2004). Use of measures with demonstrated psychometric properties would help to establish a baseline for how genetic counselors generally define a meaningful life for themselves; such data would provide a point of contrast for individual counselors. Longitudinal investigations would also yield information about the

shifts in belief and experiences of *meaning* as genetic counselors progress through their graduate training and beyond.

Quantitative methods would also allow investigators to statistically analyze individual contributions of variables such as demographic characteristics, specialty area, experience-level, supervision involvement, and career satisfaction. In addition, due to the likelihood that context influences a genetic counselor's perceptions of *meaning*, future investigators could collect data on contextual variables to further understand how perceptions shift over time. Such variables could include clinic characteristics (e.g., geographic region, availability of supervision), patient characteristics (e.g., specific health conditions, SES, education level), and broad healthcare trends (e.g., insurance parameters, societal perspectives on issues of genetic screening/testing and abortion). Examining these types of variables will help parse out which experiences of *meaning* might be shared throughout the profession and which ones depend largely on the specific context of one's practice. One obvious example could be to compare genetic counselors who see patients to those who do not. As the vast majority of the participants in this study were concurrently seeing patients, future investigators should specifically include genetic counselors who have chosen non-clinical positions (e.g., lab counselors, research coordinators, etc.) in order to assess whether there are discernible differences in their experiences of *meaning*.

The current investigation focused primarily on providing descriptions of how genetic counselors develop, experience and express *meaning* within their work. Nevertheless, it remains unknown how genetic counselors implement their insights within their work and/or receive encouragement/discouragement to utilize this construct

as deliberately informing their practice with patients. Future investigations should collect data from additional sources such as graduate educators and clinical supervisors in order to assess how various methods of training and supervision are used to introduce, discuss and embrace issues of *meaning*. Studies of this type will help to inform curriculum development and address problematic counselor performance. Finally, assessing how clinical supervisors develop, experience and express their own sense of *meaning* will also help illustrate the effect of parallel process between supervision and practice, as well as how it affects students'/ supervisees' professional development over time.

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## Appendix A: Participant Email Invitation for Online Survey

### Genetic Counselors' Views on Meaning within Their Work: An Exploratory Analysis

You are invited to participate in a research study exploring larger issues of *meaning*, especially as they relate to the interface between your personal life and your professional experiences as a genetic counselor.

This study is being conducted by: David Wells MA, a graduate student at the University of Minnesota, Department of Educational Psychology. I am working on this study with Patricia McCarthy Veach, PhD, LP and Bonnie S. LeRoy, MS, CGC also at the University of Minnesota.

**The purpose of this study is to explore issues and questions of *meaning* experienced by genetic counselors and to examine how they personally manage these issues and questions.** Everyone has ways of making sense of things that happen to them and others. I am interested in how you do this for yourself, especially as it relates to your experiences as a genetic counselor over time. For this study, participants are encouraged to think about what makes their lives feel important to them, which may or may not include things such as relationships, work, leisure and values. In addition, participants are encouraged to consider the term *meaning* within the broad scope of any religious, spiritual, existential, philosophical, or ecological realms to which they may relate.

You are invited to participate in this research study because you are currently a genetic counselor enrolled in the National Society of Genetic Counselors (NSGC) e-mail listserv. The **anonymous, on-line survey** contains 12 short demographic questions and a brief, 11-item questionnaire regarding your sense of life's *meaning*. This survey takes approximately **5 minutes to complete**. You are free not to participate or to decline answering every question. The survey can be accessed by going to the following website:

<http://edu.surveymzmo.com/s3/494630/Genetic-Counselors-Views-on-Meaning>

This survey is anonymous and the records of this study will be kept private. The final question of the survey asks that you provide your e-mail address and telephone number if you are willing to be contacted for participation in a follow-up telephone interview. Response to this question is optional. In any sort of report we might publish, it will not be possible to identify any specific participant. Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota or any of the researchers involved. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

If you have any questions about this study, you are encouraged to contact David Wells at [wells057@umn.edu](mailto:wells057@umn.edu) or 651-707-7027. You may also contact Pat McCarthy Veach ([veach001@umn.edu](mailto:veach001@umn.edu), 612-624-3580) or Bonnie LeRoy ([leroy001@umn.edu](mailto:leroy001@umn.edu), 612-624-

7193) with your questions. If you have any questions or concerns regarding this study and would like to talk to someone other than the researchers, you are encouraged to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

Again, here is the link to the survey if you are interested in participating in this survey:

<http://edu.surveygizmo.com/s3/494630/Genetic-Counselors-Views-on-Meaning>

Thank you very much for your consideration.

Sincerely,

David Wells  
Educational Psychology Student  
University of Minnesota

Patricia McCarthy Veach, PhD, LP  
Professor of Educational Psychology

Bonnie S. LeRoy, MS, CGC  
Director, Genetic Counseling Program

## Appendix B: Online Survey

### Name of the Study:

Genetic Counselors' Views on *Meaning* within Their Work: An Exploratory Analysis

### Survey Questions:

#### Demographic Questions:

1. What is your current age?
  - a. 20-25 years
  - b. 26-30 years
  - c. 31-35 years
  - d. 36-40 years
  - e. 41-45 years
  - f. 46-50 years
  - g. 51-55 years
  - h. 56-60 years
  - i. 61+ years
  
2. What is your gender?
  - a. Female
  - b. Male
  - c. Other
  - d. Prefer not to answer
  
3. Which of the following best describes your relationship status? (check one)
  - a. Single and never been married
  - b. Married
  - c. In a marriage like relationship
  - d. Separated or divorced
  - e. Widowed
  
4. Do you have any children?
  - a. Yes
  - b. No
  
5. With which ethnicity do you most identify? (check one)
  - a. African American or Black
  - b. American Indian or Alaskan Native
  - c. Asian
  - d. Bi-racial (Please specify): \_\_\_\_\_
  - e. Caucasian or White
  - f. Hispanic/Chicano/Latina(o)
  - g. Native Hawaiian or other Pacific Islander
  - h. Other (Please specify): \_\_\_\_\_
  
6. How many years have you been working as a genetic counselor?

\_\_\_\_\_ years

7. Do you currently see, or in the past 5 years have you seen, patients clinically?
- Yes
  - No
8. On average, how many patients do you currently see per week?
- \_\_\_\_\_ patients
9. What is your current specialty? (Please check all that apply)
- |                           |                      |
|---------------------------|----------------------|
| a. Cancer                 | g. Psychiatric       |
| b. Infertility            | h. Public Health     |
| c. Molecular/Cytogenetics | i. Specialty disease |
| d. Neurogenetics          | j. Teratogen         |
| e. Pediatric              | k. Other (Please     |
| f. Prenatal               | specify):_____       |
10. What is your **primary** work setting?(Please check one)
- Diagnostic laboratory
  - Federal, state, county office
  - Group private practice
  - Health maintenance organization
  - Individual private practice
  - Private Hospital or facility
  - University Medical Center
  - Other (Please specify):\_\_\_\_\_
11. In what NSGC region do you currently practice?
- Region I (CT, MA, ME, NH, RI, VT, Canadian Maritime Provinces)
  - Region II (DC, DE, MD, NJ, NY, PA, VA, WV, Quebec, Puerto Rico, Virgin Islands)
  - Region III (AL, FL, GA, KY, MS, NC, SC, TN)
  - Region IV (AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI, Ontario)
  - Region V (AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Saskatchewan)
  - Region VI (AK, CA, HI, NV, OR, WA, British Columbia)
  - Other (please specify):\_\_\_\_\_
12. With which religious or spiritual affiliation do you most identify? (check all that apply)

- a. Agnostic
- b. Atheist
- c. Baptist
- d. Buddhist
- e. Christian (Disciples of Christ)
- f. Episcopalian
- g. Friends (Quaker)
- h. Greek Orthodox
- i. Hindu
- j. Islamic
- k. Jehovah's Witness
- l. Jewish
- m. Lutheran
- n. Mormon (Church of the Latter Day Saints)
- o. Presbyterian
- p. Roman Catholic
- q. Scientologist
- r. Taoist
- s. Unitarian
- t. United Methodist
- u. Other (please specify) \_\_\_\_\_
- v. None

### 13. The Meaning in Life Questionnaire

\*Please take a moment to think about what makes your life feel important to you. Please respond to the following statements as truthfully and accurately as you can, and also please remember that these are very subjective questions and that there are not any right or wrong answers. Please answer according to the scale below:

Absolutel Untrue 1	Mostly Untrue 2	Somewhat Untrue 3	Can't Say True or False 4	Somewhat True 5	Mostly True 6	Absolutely True 7
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1. \_\_\_\_\_ I understand my life's meaning.
2. \_\_\_\_\_ I am looking for something that makes my life feel meaningful.
3. \_\_\_\_\_ I am always looking to find my life's purpose.
4. \_\_\_\_\_ My life has a clear sense of purpose.
5. \_\_\_\_\_ I have a good sense of what makes my life meaningful.
6. \_\_\_\_\_ I have discovered a satisfying life purpose.
7. \_\_\_\_\_ I am always searching for something that makes my life feel significant.
8. \_\_\_\_\_ I am seeking a purpose or mission for my life.
9. \_\_\_\_\_ My life has no clear purpose.
10. \_\_\_\_\_ I am searching for meaning in my life.

14. May we contact you for clarification and further discussion of your responses (i.e. a discussion regarding aspects of your experiences of life's *meaning*, especially as they relate to your work as a genetic counselor)?

If so, please provide the following:

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Thank you very much for participating in this survey!

## Appendix C: Interview Questions/Script

### Introduction to the Telephone Interview:

“The purpose of this study is to explore issues and questions of *meaning* experienced by genetic counselors and to examine how they personally manage these issues and questions. Everyone has ways of making sense of things that happen to them and others. I am interested in how you do this for yourself, especially as it relates to your experiences as a genetic counselor over time. For this study, participants are encouraged to think about what makes their lives feel important to them, which may or may not include things such as relationships, work, leisure and values. In addition, participants are encouraged to consider the term *meaning* within the broad scope of any religious, spiritual, existential, philosophical, or ecological realms to which they may relate.”

#### *\*7 major questions with available interviewer prompts in italics\**

“Before jumping into the interview, I would like to spend just a few minutes answering any questions that you may have for me and verifying your demographic information from the survey portion of the study. Is this alright with you?”

- 1) How might you define a meaningful life for yourself?
  - a. *Provide any examples of beliefs, values, and activities that provide this meaning.*
- 2) What or who have been influences on the development of your views on life’s *meaning*? In other words, what or who has shaped your views about life’s *meaning*?
  - a. *Personal relationships, professional relationships, religious/spiritual/existential influences, personal experiences of health/illness/loss, and having children.*
- 3) What types of issues related to *meaning* arise for you in your work as a genetic counselor?
  - a. *What are the contexts in which meaning (in as far as you have defined it for yourself) arises in your work?*
- 4) Can you describe a situation from your work as a genetic counselor that has challenged your personal views on *meaning*?
  - a. *What was the context?*
  - b. *What issues of meaning arose?*
  - c. *How did you address this situation for yourself?*
- 5) Can you describe a situation from your work as a genetic counselor that has reaffirmed your personal views on *meaning*?
  - a. *What was the context?*
  - b. *What issues of meaning arose?*
  - c. *How did you address this situation for yourself?*

- 6) Let's take a little time to explore your current views on *meaning* as discussed so far and compare them with when you first started your work as a genetic counselor. How have these views on *meaning* stayed the same over time and how have they changed since you first started your work in this field?
    - a. *What has allowed for this stability?*
    - b. *What has allowed for this change?*
  - 7) What personal *meaning* do you derive from what you do as a genetic counselor?
    - a. *What does it mean to you to be helpful in your profession?*
    - b. *What do you get out of what you do?*
  - 8) What, if anything, prompted your decision to participate in this study?
  - 9) In wrapping up, are there any aspects of your personal sense of *meaning* that we have not discussed that you would like to mention now? Or, are there any points that you would like to reiterate as you reflect upon this interview?
- “\_\_\_\_\_ , thank you so much for your participation in this study! I very much appreciate your thoughtful responses regarding what makes your life feel important to you and how this relates to your work as a genetic counselor.”

## Appendix D: Participant Email Invitation for Telephone Interview

**Subject Line:**

Genetic Counselors' Views on Meaning ... Study participation follow-up

**Body:**

Hello,

My name is David Wells, and I am the doctoral student at the University of Minnesota who is conducting the study "Genetic Counselors' Views on Meaning within Their Work: An Exploratory Analysis" under the supervision of Pat McCarthy-Veach, PhD, LP and Bonnie LeRoy, MS, CGC.

I want to thank you sincerely not only for completing my initial survey but also for providing your contact information for a follow-up interview. I also want to let you know that I am in the second and final round of recruiting individuals to complete the survey portion of my study. Shortly thereafter, I will be contacting a subset of those who have provided contact information to schedule a telephone interview. In addition, I am planning to add a longitudinal component to this study. If approved by my university's IRB, this will involve adding one question at the end of the telephone interview, asking participants if they would be willing to be contacted again for another interview sometime during the next 1-2 years. Participation in this potential longitudinal design would also be voluntary.

So, I look forward to contacting a number of you over the course of the next few weeks to schedule some time (i.e., approximately 30-45 minutes) to complete our follow-up telephone interview regarding larger issues of *meaning* and how they relate to the interface between your personal life and your professional experiences as a genetic counselor. In contacting you, I will likely begin with an individual e-mail, but will call you by telephone during the times you provided, if necessary.

Again, thank you for volunteering to participate in my study. I very much look forward to speaking with you soon!

Sincerely,

David Wells

## Appendix E: Consent Form Emailed to Interviewees

### Name of the Study:

Genetic Counselors' Views on Meaning within Their Work: An Exploratory Analysis

You are invited to participate in a research study exploring larger issues of *meaning*, especially as they relate to the interface between your personal life and your professional experiences as a genetic counselor. You were selected as a possible participant because of your personal experience working in a genetic counseling setting.

This study is being conducted by: David Wells MA, a graduate student at the University of Minnesota, Department of Educational Psychology. I am working on this study with Patricia McCarthy Veach, PhD, LP and Bonnie S. LeRoy, MS, CGC at the University of Minnesota.

### Background Information

**The purpose of this study is to explore issues and questions of *meaning* experienced by genetic counselors and to examine how they personally manage these issues and questions.** Everyone has ways of making sense of things that happen to them and others. I am interested in how you do this for yourself, especially as it relates to your experiences as a genetic counselor over time. For this study, participants are encouraged to think about what makes their lives feel important to them, which may or may not include things such as relationships, work, leisure and values. In addition, participants are encouraged to consider the term *meaning* within the broad scope of any religious, spiritual, existential, philosophical, or ecological realms to which they may relate. The importance of this study relates directly to the literature on practitioner professional development, reflective practice, and burnout. Results from this study will also assist training programs in creating and maintaining effective curricula based on self-reflection as a developmental process within this unique counseling field.

### Procedures

If you agree to be in this study, we would ask you to do the following things:

1. Complete an initial **5-10 minute anonymous online survey** questionnaire containing demographic questions and questions regarding your sense of life's *meaning*.
2. Consider providing your contact information for possible participation in one, 30-45 minute telephone interview discussing aspects of your experiences of life's *meaning*, especially as they relate to your work as a genetic counselor. All interviews will be audio taped and transcribed. After the tapes are transcribed, all identifiers will be removed.

### Risks and Benefits of being in the Study

There are no major risks involved in this study. Efforts were taken to word survey and interview questions in both an open-ended and value-neutral format. However, participants will be given the option to withdraw from questioning or refuse to answer any or all questions that they feel are not appropriate for their situation.

Potential benefits to participation in this study are that data obtained may provide insight into the types of issues of purpose and *meaning* that arise within the scope and practice of genetic counseling and what counselor strategies might be helpful in exploring or addressing these issues in their work. This information will also assist training programs in their efforts to enhance genetic counselor development.

**Compensation:**

You will not receive payment for participating in this study.

**Confidentiality**

The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify you. Research records and any audio taped materials will be stored securely and only researchers will have access to the records. The tapes will not be used for educational purposes. All records will be erased upon completion of the study.

**Voluntary Nature of the Study**

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

**Contacts and Questions**

If you have any questions about this study, you are encouraged to contact David Wells at [wells057@umn.edu](mailto:wells057@umn.edu) or 651-707-7027. You may also contact Pat McCarthy Veach ([veach001@umn.edu](mailto:veach001@umn.edu), 612-624-3580) or Bonnie LeRoy ([leroy001@umn.edu](mailto:leroy001@umn.edu), 612-624-7193) with your questions.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researchers, you are encouraged to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

## Appendix F: Bias Bracketing Documents

### Expectations for Open-Ended Responses

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**Study Title:** *Development, Experience and Expression of Meaning in Genetic Counselors' Lives: An Exploratory Analysis*

#### **Overall**

- I expect the responses will be highly articulate, deep, and insightful. I also expect their work as genetic counselors to have an impact on their views and values. I expect the views of participants to be highly liberal and open minded. I think that GCs will be fairly open to talk about their deeply held beliefs and be able to analyze and determine how their actions affect others. I foresee the amount of time GCs have worked in the field as having an effect on the amount participants will be able to reflect and think about how their work has impacted their worldviews and how they define a meaningful life.

#### **Definitions of meaning**

- I expect participants will define meaning in profound and distinct ways that are related to their faith, their work and their personal relationships.

#### **Sources/influences on meaning**

- Responses will likely surround family and personal relationships. Being in a helping profession, they will likely value relationships and caring for others.

#### **Meaning contexts in GC work**

- I foresee answers to this question being about helping others and feeling content and rewarded by providing support for others in need.

#### **Specific GC challenges to meaning**

- I expect that their work will challenge their conception of meaning and working with diverse clients in difficult situations will create change. GCs will inevitably see clients with differing views and have to see issues from other perspectives.

#### **Reaffirmed meaning**

- I do not know what to expect for this question. I think people will have fewer reaffirmations than challenges to meaning due to the diverse clientele they are serving. Clients with different views and practices may cause them to be more critical of their own beliefs and consider alternate ways of living.

#### **Changes in meaning over time**

- I think that participants will have made a few alterations to their views on meaning based on their work. I think that the older the participant is, the more change they will have had the chance to experience experienced.

#### **Why this study?**

- I think participants will be excited to reflect on their work and life. I also expect people to want to help out in a research study because they have been in the position of researcher and know how hard it can be to gain participants.
- 

Researcher: Daniel Cooper

Date: 10/17/2013

## **Expectations for Open-Ended Responses**

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**Study Title:** *Development, Experience and Expression of Meaning in Genetic Counselors' Lives: An Exploratory Analysis*

### ***Overall***

- I presume the participants will initially struggle with the interview questions, feeling they are very broad. However, I think receiving the questions in advance will allow the individuals to feel more prepared and confident in their answers. When identifying life meaning as a whole, I am predicting the participants to be challenged to maintain a balance between their career and the professional identity which was created along the way, and with their personal life and interpersonal relationships. In addition, I believe the amount of experience the participant has as a Genetic Counselor will greatly impact their perspective of challenges and change within themselves.

### ***Definitions of meaning***

- I anticipate the participants will define meaning in a variety of ways, with an emphasis in interpersonal relationships and helping others.

### ***Sources/influences on meaning***

- I predict the participants will identify their personal relationships as well as professional relationships as their main source of meaning.

### ***Meaning in contexts in GC work***

- I expect the participants to feel the meaning of their work mainly stems from helping others, providing empowerment and using their own knowledge to educate others on difficult, life changing decisions.

### ***Specific GC challenges to meaning***

- I believe the participants will state they struggle the most in maintaining clear boundaries between their personal values, and the values of their patients.

### ***Changes in meaning over time***

- I foresee this category greatly depending on the experience of the Genetic Counselor. The more years the individual has held this role, the more change they will report due to natural maturation. The less years an individual holds, the less they will feel has changed to their definition of meaning.

### ***Why this study?***

- I assume, especially in this field of work, the individuals will chose to be involved in this study as a way to be helpful, similar to what they believe provides them with a sense of meaning.

Researcher: Lindsey Benolken

Date: 10/17/2013

## Expectations for Open-Ended Responses

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**Study Title:** *Development, Experience and Expression of Meaning in Genetic Counselors' Lives: An Exploratory Analysis*

Generally speaking, I believe that the interviewees are going to present as thoughtful in their responses to questions based on their motivation to self-select into the interview in the first place. I also believe that they will be notably intelligent and articulate in their responses based on their shared graduate-level education.

I also believe there will be some notable themes in participants' responses to the interview questions themselves due to the dual nature of the genetic counseling profession itself; namely the scientific and patient-centered aspects of the field. Related to the scientific domain of genetic counseling, I suspect that many participants will speak to their interest and/or passion for hard sciences. This may take the form of a general desire for knowledge and an appreciation for one's ability to understand and/or communicate facts based in biology and genetics. Related to the patient-centered domain of the counseling work, I suspect that many participants will speak to the importance of relationships and helping others on their overall sense of meaning. While my guess is that most people (even outside of the genetic counseling field) would note relationships and helping others as meaningful, it is my belief that the participants having chosen to work within this helping profession specifically will make this obvious within their responses. Similarly, I believe that their status as genetic counselors will make participants likely to speak to the importance of empathy and patient stories as being integral to their sense of meaning.

I also have a few expectations for participant responses based in my own professional experiences as a counselor, albeit within a more traditional mental health (i.e., non-genetic counseling) domain. For example, I feel my own personal sense of meaning challenged when I work with clients with values very different than my own and when I feel limited in my ability to provide concrete help to my clients. Consequently, I believe that these same types of scenarios will be prevalent in genetic counseling participants' patient anecdotes. Also, as I feel that I have become more open-minded and developed an increased tolerance for ambiguity in my own counseling work as compared to when I first entered the profession, I suspect more seasoned genetic counseling participants will talk about how they have an increased ability to go with the flow with stressful patient situations and to see the bigger picture (i.e., beyond any one fundamental truth) when working with diverse patients.

Researcher: David Wells

Date: 10/17/2013