

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

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**Abstract** Genetic counselors routinely engage with patients and families who grapple with questions of *meaning* while making decisions about genetic risk. Research and theory demonstrate genetic counselors gain important personal insights through their work and develop professionally from self-reflective practice regarding their beliefs and values. Data are lacking, however, about the nature of the *meaning* genetic counselors bring to their 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 brief survey assessing their 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) how they experience *meaning* within both personal and professional contexts; 4) work-related contexts that reaffirm and challenge their sense of *meaning*; and 5) how their sense of *meaning* has changed over time. Twenty-five interviews were analyzed using Consensual Qualitative Research methods, at which point, data saturation was reached. Five themes, 32 domains,

and 29 categories were extracted. Common findings include: 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, practice implications, and research recommendations are presented.

**Keywords** Meaning · Purpose · Professional development · Genetic counselor · Qualitative study

*There was this family who had a baby with a very severe...problem...This was a family that was very strong in their faith and very positive...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...They decided they were again pregnant but would go against their religious beliefs...because they just could not bring another baby into the world with the same condition. So, they pursued testing. And the day that I called the mother to give her the results that the unborn baby was also affected, her [first] child died. The family chose to pursue termination. They really felt they had no other option. 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...*

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*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.* – Excerpts from Genetic counseling participant

As evident in this patient vignette, genetic counseling sometimes presents as many challenges as it does rewards for practitioners. When genetic counselors place themselves in the shoes of this couple, they may ask themselves a variety of questions about the fundamental *meaning* of the situation. For example: 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 a complex, emotional, and existential patient journey? Does my own history allow me to empathize more deeply, thereby strengthening my ability to provide them with the authentic psychosocial support they need?

Despite a growing body of literature on genetic counselor professional development (e.g., Abrams and Kessler 2002; Kessler 1992; McCarthy Veach et al. 2002; McCarthy Veach and LeRoy 2012; Resta 2002; Miranda et al. 2015; Runyon et al. 2010; Zahm et al. 2015), no empirical research has explicitly and comprehensively investigated the extent to which genetic counselors experience their own sense of *meaning* and how this meaning 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* in their work. Therefore, the present study explored genetic counselors' views on *meaning* as they relate to their clinical work and professional development. This study was designed to generate data to provide an initial framework in which to understand the importance of issues of *meaning* to the training, supervision, and practice of genetic counselors. Grounded in existential philosophical beliefs (cf. Frankl 1984; Sartre 2007; Yalom 1980), the study derives from a premise that self-reflection on issues of *meaning* is a necessary tool to enhance genetic counseling practice. We begin by describing some historical underpinnings of existentialism as they relate to the construct of *meaning* and how existential thought has been connected to helping professions such as counseling. Next we review genetic counselor professional development literature to argue for parallels between reflective practice and integration of personal and professional selves with the construct of *meaning*.

## An Existential Foundation of *Meaning*

Viktor Frankl, a well-known psychiatrist and neurologist, built an existential foundation for psychotherapy following his experiences as a concentration camp inmate in Germany. Frankl (1984) suggests one's life is never made inevitably

unbearable by circumstances alone, but instead becomes unbearable when a person lacks a sense of *meaning* and/or purpose about suffering. He also argues that the journey to discover a true sense of *meaning* serves as a person's primary motivation in life. In this regard, he echoes Friedrich 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 emphasizes there is no single or universal *meaning* in life; each person is responsible for developing his or her own through a life-long journey of self-reflection. 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).

Speaking similarly about the construct of *meaning*, existential author and psychotherapist, Irvin Yalom (1980, 2002, 2008) postulates humans possess four ultimate concerns about their existence that precipitate anxiety: (1) *Death*; (2) *Freedom* - true existential freedom involves a painful realization that we do not exist in a well-defined universe and that having unlimited choices is burdensome; (3) *Isolation*; and (4) *Meaninglessness* - we have a need to establish some sense of *meaning* within our lives.

Existential theorists assert that counselors working with clients engaged in an intimate journey of self-discovery experience a range of emotions, not only privilege and joy but also vulnerability and distress. Farber and Heifetz (1981) note counselors are "like the shamans and healers of other cultures [who] both prosper and suffer from their calling" (p. 629). Yalom (1989) postulates that one of the greatest benefits therapists can gain is learning from and being helped by clients.

Existential themes are useful in appreciating the deep, substantive connections made by the genetic counselors 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 they would 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 they would apply similar 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.

## Issues of Meaning in Genetic Counselor Professional Development and Practice

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), and they appear to learn a great deal about themselves in the process (Runyon et al. 2010). Their experiences may promote positive professional development in the form of enhanced empathy, strengthened self-esteem, improvement of clinical skills, and development of expertise (Miranda et al. 2015; Runyon et al. 2010; Zahn et al. *in review*). Their experiences may also result in negative outcomes such as burnout and compassion fatigue (e.g., Injeyan et al. 2011; Lee et al. 2014; Udipi et al. 2008).

Zahm et al. (2015) examined professional development of 34 genetic counselors and found a commitment towards self-reflection about meaningful experiences in their personal lives led to deeper self-understanding, a stronger work-life balance, increased self-care, and enhanced boundaries. They also found genetic counselors tended to experience intense and profound lessons from direct interactions with patients (often based on patients' suffering and related resilience), drew from their own personal lives to inform their work with patients, developed sophisticated ways to conceptually connect their individual experiences to extract *meaning* from them, and developed an integrated sense of self over the course of their careers. Although not explicit, there is a strong connection between these themes and the current investigation's focus.

Miranda et al. (2015) interviewed 15 master genetic counselors to explore their personal characteristics, professional strengths and struggles, and views of their professional development. Particularly relevant to the present study, they found master genetic counselors are self-reflective and self-aware, and they are affected emotionally by their work but use varied coping mechanisms to manage their reactions. Although the researchers did not directly ask participants to describe what is personally meaningful, the data provide rich descriptions of potentially important components such as personal motivations and inspirations. The findings suggest there are 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 existential factors (e.g., isolation and meaninglessness).

Similar to Zahm et al. (2015) and Miranda et al. (2015), models of genetic counseling practice, such as the Reciprocal-Engagement Model (REM) (McCarthy Veach et al. 2007), note the importance of practitioner self-reflection. Self-reflection helps to promote 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" (p. 726). In the REM, genetic counselors must be "reflective practitioners, who are self-aware, ethical, objective to the extent possible, and open and responsive to feedback" (p. 721). 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). 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 sense of *meaning* influences counseling processes and outcomes.

Relatedly, Pirzadeh et al. (2007) asserted that clinicians' self-awareness regarding their personal values may influence presentation of facts and decision options to patients, as well as whether they invite patients to consider moral consequences related to their decisions. These researchers found genetic counselors highly valued benevolence, self-direction, achievement, and universalism, while 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) was the fourth lowest ranked value. Research has shown religiosity and spirituality play important roles for many people, especially when faced with stressful life experiences (Bjork and Thurman 2007; Pargament 1997; Zinnbauer et al. 1997). Within the context of genetic counseling, patients commonly consider these same constructs while making decisions about genetic testing, pursuit of treatment, and pre-term abortion (Schwartz et al. 2000; White 2006). Moreover, a majority of genetic counselors in another study identified themselves as moderately to highly spiritual (Cragun et al. 2009). Despite equivocal findings, it is important to consider the significance of these constructs for genetic counselors' sense of meaning.

Finally, McCarthy Veach and colleagues (2002, 2012) published two series of "Defining Moments Essays," genetic counselor descriptions of meaningful catalysts to their personal and professional development. The authors variously describe their experiences as mothers, students, and patients, as well as momentous professional experiences. McCarthy Veach and LeRoy (2012) argue that the power in genetic counselors' defining moments comes from "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).

## Purpose of the Present Study

The purpose of this study was to examine the nature of *meaning* for genetic counselors. A primary intention was to garner a more holistic perspective of how genetic counselors develop, experience, and express the construct of *meaning* throughout their work (and lives). There were five 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? (4) What are some particular work-related contexts that have challenged and reaffirmed their personal views on *meaning*? and (5) How has their sense of meaning changed over time?

## Method

### Sample

Upon receipt of approval from the University of Minnesota Institutional Review Board, participants were recruited through an electronic invitation sent to members of the National Society of Genetic Counselors (NSGC) listserv. The invitation described this research as a study exploring larger issues of *meaning*, especially as they relate to the interface between one's personal life and professional experiences as a genetic counselor, and it contained a link to a survey. The invitation was sent twice in April 2011, and a total of 298 individuals completed the online survey. Of those, 92 expressed willingness to be contacted for an interview.

Using purposive sampling, we selected 70 individuals from whom 68 completed an interview. Individuals reporting certain low-incidence demographic characteristics (male, ethnic minority, >20 years of experience, certain religious identifications) were first over-selected. Additional participants were selected to approximate the proportions of other demographic characteristics present in the survey sample. Although 12–15 interviewees typically are sufficient to achieve data saturation (Hill 2012), we conducted more interviews for three primary reasons: (1) The abstract nature of the topic might make it more difficult to extract highly differentiated and prevalent domains within a small sample (Morse 2000); (2) More interviews allowed for inclusion of individuals from each of 10 genetic counseling sub-specialties represented among survey respondents; and (3) Given the seemingly strong interest in participating in an interview, we wished to maximize the opportunity for genetic counselors to have their voices heard.

The first author, in consultation with the second and fourth authors, purposively identified 25 interviews for inclusion in the final data analysis, using similar selection criteria as described above for selection of the interviewee sample, and an additional criterion – interviews that were particularly engaging and/or unique. The first author listened to every interview to assure no unique themes were missed.

### Instrumentation

#### *Online Survey*

The authors created an online survey comprised of 12 demographic items; the *Meaning in Life Questionnaire* (Steger et al. 2006; which is not part of the present analysis); and a final item inviting respondents to provide contact information if they were willing to be contacted for an interview. Piloting of the survey with two advanced genetic counseling students resulted in minor wording changes.

#### *Interview Questions*

Nine open-ended questions and related prompts (See Appendix) were developed based on a review of relevant literature and the authors' clinical and research experience. The questions asked about interviewees' personal sense of *meaning*, sources of influence on meaning, how they experience *meaning* within their genetic counseling practice, and why they chose to participate in the study (the latter question is not part of the present analysis). Piloting of the interview guide with two advanced genetic counseling students resulted in minor changes to improve the clarity of a few questions.

### Interview Procedures

Participants were contacted by the first author to schedule an audio-recorded phone interview. They were sent the interview questions to review prior to the interview. The first author conducted interviews between April–August, 2011. Interviews were transcribed verbatim.

### Data Analysis

#### *Survey Data*

Frequencies and sample sizes were computed for survey items.

#### *Interview Data*

The data analysis team consisted of the first author and two masters level graduate students in psychology. They received basic training in Consensual Qualitative Research (CQR) methods (Hill 2012; Hill et al. 1997, 2005), an overview of the genetic counseling field, and the interview questions in order to familiarize them with the scope of the project and to facilitate bracketing of their expectations/biases prior to data analysis.

Using CQR methods, each team member independently coded responses for three randomly selected transcripts. They developed *domains* (topic areas), constructed *core ideas* (summaries of interview content), and *categories* (specific topics

within domains). They engaged in cross-case analysis to identify domains and categories represented across transcripts. Next they met to discuss and reach consensus on their classifications. They repeated this process for another two randomly selected transcripts. Preliminary domains and categories from the first five transcripts served as a guide to analyze the remaining 20 transcripts. The first author analyzed all of the remaining transcripts, and each master's student also analyzed a portion of those transcripts. The team met regularly to reach consensus on their classifications. A data auditor, the second author, reviewed data classifications. Disagreements were discussed to reach consensus.

## Results

### Participants

A total of 298 genetic counselors completed the initial survey. Based on the estimated number of members enrolled in the NSGC listserv ( $\sim N=1400$ ), the response rate was 21 %. Of those who completed the initial survey, 31 % ( $n=92$ ) consented to participate in a follow-up interview. Demographic characteristics for all survey respondents, as well as for those chosen for interviews and those not chosen for interviews are presented in Table 1. Demographic characteristics for the total sample appear to be generally consistent with those reported in an NSGC Professional Status Survey conducted around the time of this study (NSGC 2012); and interviewees and non-interviewees generally appeared to be similar demographically to the total sample. Statistical analyses could not be conducted, however, as over-selection of certain low-incidence variables (e.g., male gender) intended to assure representation in the interviews, violated assumptions of independence for chi-square tests.

Demographic characteristics for those participants whose interviews were chosen for data analysis ( $n=25$ ) and those not chosen for data analysis ( $n=63$ ), are presented in Table 2. Most of the interviewees were Caucasian and female, between 20 and 40 years old, in a marriage-like or married relationship, and did not have children. The most prevalent religious/spiritual affiliations were Roman Catholic, Agnostic, Christian (Disciples of Christ), and None. The interviewees varied in their years of genetic counseling experience and geographic region. The most prevalent practice settings were university hospital, private hospital, and diagnostic lab, and the most common specialties were prenatal, pediatrics, and cancer.

### Interview Characteristics

Interviews ranged from 15 to 50 min (median=34.5 min). It was the interviewer's impression that every participant approached the interview with openness, engagement, self-

reflection, a conversational style, and a balance between seriousness and humor. Consequently, most counselors independently provided rich responses with minimal prompting or requests for clarification. Some mentioned it was beneficial having received the questions for advance review. The interviewer sensed that a few counselors had prepared written responses, which resulted in truncated statements and less spontaneity in some replies. While most counselors primarily drew upon an intellectual framework when responding, many also provided emotional responses often centered on humor, hope, sadness, grief, frustration, gratitude and love. Some individuals also cried while discussing experiences of personal loss and/or hardship, challenging patient scenarios, or feelings of empowerment.

### Results of CQR Analysis of Interviewee Responses

Interview results are organized according to five thematic areas closely aligned with the interview questions (see Appendix): General definitions of a meaningful life, Sources and/or influences on one's sense of *meaning*, Specific contexts of *meaning* experienced within genetic counseling practice, Specific challenges to *meaning* experienced within genetic counseling practice, and Changes in *meaning* over time. Thirty-two domains and 29 categories were extracted from responses and are presented in Table 3. Responses typically were complex, resulting in classification within multiple domains and/or categories. Domains are described next, and representative quotations for each domain that had  $\geq 8$  responses are provided.

#### Theme 1: General Definitions of a Meaningful Life

Participant descriptions of how they define a meaningful life for themselves yielded six domains: Satisfying relationships, Service to others, Fulfillment, Making an impact, Work/life balance, and Self-realization.

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

Most counselors identified satisfying connections with others as an important contributor to their sense of *meaning*. These included individual relationships with family members, friends, and coworkers as well as broad connections to communities of people:

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. 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

**Table 1** Demographics of interviewees ( $n=68$ ), non-interviewees ( $n=230$ ) and survey respondents ( $N=298$ )

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 relationship	49	72.1	131	57.0	180	60.4
Married	7	10.3	48	20.9	55	18.5
Single and 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 (Disciples 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
Years of genetic counseling experience						
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

**Table 1** (continued)

Variable	Interviewees		Non-interviewees		Total sample	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
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

<sup>a</sup> Respondents could check all that apply; *n* varies slightly as not all participants answered every item

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 to improve the lives of others contributes to their sense of *meaning*. Helping by serving others and providing them with emotional support through listening and compassion provide personal *meaning*:

...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.  
...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].

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

Over half of the sample said participation in interesting activities, general feelings of contentment, and attainment of knowledge contribute to their well-being and *meaning*. Enjoyable activities at work and at home foster feelings of engagement, enjoyment and purpose: "*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).*" Life satisfaction, feelings of well-being, and a drive to learn, be reflective, and enhance one's general understanding of the world contribute to meaningful living:

What's meaningful is when I can just take a step back from the hustle and 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...I feel that was what it was about.  
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.

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

Many participants stated that a meaningful life involves leaving some sort of mark or legacy, including having a modest impact on the world around them:

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.  
...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.

#### *Domain 5: Work/Life Balance (n= 7)*

A few counselors described a meaningful life as striving for balance between personal and professional endeavors, so as to avoid being discontent, overwhelmed, or one-dimensional.

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

Some counselors commented that their efforts towards personal improvement (reaching their potential) and capitalizing on their strengths (skills/gifts) contribute to a sense of *meaning*.

### **Theme 2: Sources and/or Influences on One's Sense of Meaning**

Responses to an interview question about sources of influence on one's views of meaning yielded six domains: Health/illness/loss, Religious/spiritual contexts, Personal relationships, Professional relationships, Personal values, and Biology. Overall, this interview question was difficult for participants to consider without the scaffolding of available prompts. Nevertheless, they provided many rich examples, and this was the question for which some counselors became noticeably emotional and increasingly self-reflective when responding.

#### *Domain 1: Health/Illness/Loss (n= 23)*

All but two individuals described having redefined their sense of *meaning* during or after an important struggle with illness or loss for themselves or others. For many, their redefinition resulted in increased empathy about life and loss, greater appreciation of their own health and resilience, and/or gratitude for not having notable health concerns or losses:

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.  
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 everything that you knew before that time is just totally different.

**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	
	<i>n</i>	%	<i>n</i>	%
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 relationship	17	68.0	32	74.4
Married	3	12.0	4	9.3
Single and 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 (Disciples 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
Years of genetic counseling experience				
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

**Table 2** (continued)

Variable	Data analyzed		Data not-analyzed	
	<i>n</i>	%	<i>n</i>	%
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

<sup>a</sup> Respondents could check all that apply; *n* varies slightly as not all participants answered every item

I have had many friends who have struggled with many illnesses... 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.

...lack of illness or tragedy in my family and my loved ones [is 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.

#### Domain 2: Religious/Spiritual Contexts ( $n=23$ )

Almost everyone described the influence religious and/or spiritual foundations have had on their current sense of *meaning*.

**Table 3** Themes, domains, and categories extracted from interviewee responses ( $n=25$ )

Theme, domain/category	$n^a$
<b>Theme 1: General definitions of a meaningful life</b>	
Satisfying relationships	17
Individual relationships	15
Sense of community	4
Service to others	15
Generally being helpful	11
Being emotionally present	7
Fulfillment	14
Pursuing passions	9
General contentment	6
Gaining knowledge	5
Making an impact	10
End of life reflection	5
Making the world better	4
Work/life balance	7
Self-realization	5
Reaching potential	4
Using skills/gifts	3
<b>Theme 2: Sources and/or influences on one's sense of meaning</b>	
Health/illness/loss	23
Personal issues	15
Others' issues	8
Lack of issues	5
Religious/spiritual contexts	23
Positive experiences/background	14
Detachment	8
Shift from religion to spirituality	6
Personal relationships	21
Family	18
Friends	9
Cultural group	2
Professional relationships	17
Colleagues	12
Supervisors	8
Patients	2
Personal values	9
Biology	4
<b>Theme 3: Specific contexts of meaning experienced within genetic counseling practice</b>	
Helping others	23
General support	21
Imparting information	17
Patient empowerment	14
Provision of resources	9
Vicarious lessons	11
Development of empathy	10
Appreciating individual differences	10

**Table 3** (continued)

Theme, domain/category	$n^a$
Validation through gratitude	10
Human connection	9
Intellectual challenge	8
Resiliency	8
Miscellaneous	3
<b>Theme 4: Specific challenges to meaning experienced within genetic counseling practice</b>	
Value conflicts	14
Discomfort with loss/suffering	10
Competing obligations and priorities	8
Accepting that bad things happen	7
Lack of control	7
Limited resources	2
<b>Theme 5: Changes in meaning over time</b>	
Deemphasized individuality	12
Increased humility	7
Increased recognition of the value of relationships	6
General maturation	10
Equanimity	7
Help takes many forms	6
Miscellaneous	5

$n^a$  refers to number of comments

For some their foundation included a strong affinity for religious practice throughout their lives, while for others, unpleasant/unsatisfactory experiences prompted a detachment from religion and/or development of a broader spiritual identity over time. Whether or not they fully detached from religious participation, a few counselors found a deeper sense of *meaning* within broader spiritual practices compared to organized religion:

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 comes from there.

When I was younger, I was very active in a religious upbringing...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 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...

### Domain 3: Personal Relationships (n= 21)

A large majority of counselors noted relationships within their personal lives have served as historical sources and/or current influences on *meaning*. These relationships involve immediate family (including children), extended family, friendships, and broader cultural groups:

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 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].

...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... when you need them.

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 genetic counseling field have served as important sources of influence on their sense of *meaning* over time. Influential sources included coworkers or associates within the broader profession, supervisors, professors, mentors, and patients:

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 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].

Genetic counseling is one of those professions where there are pretty inspiring people in the field...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.

There are times in peoples' lives, very vulnerable times, when you're 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 as it is, keeps me plugged into that bigger picture.

### Domain 5: Personal Values (n= 9)

Several participants described personal values and/or beliefs that have influenced their sense of meaningful living. For instance, "[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?"

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

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

## Theme 3: Specific Contexts of *Meaning* Experienced within Genetic Counseling Practice

Responses to questions about issues regarding meaning that arise in clinical work and the meaning participants derive from their work yielded nine domains: 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 interviewees stressed that they experience *meaning* through their clinical work. Feeling they are directly improving others' lives in some way validates their desire to help people or improve the world. As mentioned in previous domains, help includes 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'"; and:

[My grandmother used to say] “The joy that isn’t shared dies young.” But I think I try to take 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.

Help also includes educating patients about diagnosis, disease-etiology, and/or biological risk (e.g., “...for those families who are really feeling alone, it’s a huge gift to be able to give them an answer”; and “...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”); finding ways to strengthen patients’ sense of autonomy so they feel more in control of their situations, and/or are able to make better-informed decisions (e.g., “... if I can give them...even a glimmer of understanding or control through that understanding, then I feel like I have provided something meaningful for them”); and meeting their patients’ needs by connecting them with support, specific procedures, and/or services (e.g., “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...that goes into my meaning as a genetic counselor.”)

#### Domain 2: Vicarious Lessons (n= 11)

A number of counselors noted difficult patient situations challenge them to reflect upon how they might deal with similar scenarios in their own lives, and in doing so, they learned more about themselves:

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...very enlightening as I go through my career. Every situation has some kernel that I can pull out.

#### Domain 3: Development of Empathy (n= 10)

Several 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 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.

#### Domain 4: Appreciating Individual Differences (n= 10)

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

...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 [to see] every case as new.

#### Domain 5: Validation Through Gratitude (n= 10)

For several interviewees, *meaning* comes from the positive feelings and validation they experience when patients communicate their appreciation:

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 they tell me that I’ve helped them through it, that’s just the best feeling in the world.

#### Domain 6: Human Connection (n= 9)

Opportunities to connect in substantial and memorable ways with patients and colleagues, usually through stories and a shared mission, provide meaning for a number of counselors:

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 derived *meaning* from the mental stimulation that comes from feeling they are learning, engaged and

productive while working. A number mentioned the stimulation that comes directly from mastering a complicated science:

Genetics is really complicated! And so it gives me personal meaning to know I'm using all of the neurons that are up there. 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; 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 said increased awareness of and appreciation for people's inherent resilience provided them with *meaning*. They noted patients' abilities to bounce back from adversity and grow stronger through their suffering (e.g., "There's an admiration as to how those people manage to get through and handle it with grace and dignity and a positive attitude. It's just quite amazing to me, the strength of character that some people are able to show").

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

Three interviewees provided responses that could not otherwise be classified, including having opportunities to see underlying positive qualities in others and to provide meaningful experiences for other genetic counselors.

### **Theme 4: Specific Challenges to *Meaning* Experienced within Genetic Counseling Practice**

The sample's description of specific challenges to meaning within practice 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)*

Many counselors described how their *meaning* has been challenged when working with patients whose values differ noticeably from their own. A few emphasized the importance of striving to manage their discomfort in order to allow patients to make autonomous decisions:

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 2: Discomfort with Loss/Suffering (n= 10)*

Several counselors said their sense of *meaning* within their work is challenged when they feel uncomfortable with patients' pain and suffering. Examples included countertransference, 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.

#### *Domain 3: Competing Obligations and Priorities (n= 8)*

Several counselors noted their sense of *meaning* is challenged when they feel torn between conflicting expectations of patients, supervisors, medical doctors, society, and/or their personal lives. Some expressed hopelessness about the current situation improving:

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 12, 15 h a day, and not having a moment for my family because anytime I'm 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 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 job].

#### *Domain 4: Accepting that Bad Things Happen (n= 7)*

Some counselors said their *meaning* is challenged when they realize how much suffering is in the world and how life is unfair. They strive to manage this reality without feeling defeated.

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

Feeling limited in one's ability to inspire change at an individual and/or discipline-wide level has posed challenges to meaning for several counselors. For instance, when patients "refuse" to make a decision, some counselors experience frustration because they feel as if they were not helpful to them.

*Domain 6: Limited Resources (n=2)*

Two individuals commented that their sense of *meaning* is challenged by what they see as limitations inherent to the field of genetic counseling, compared to other fields of practice.

**Changes in Meaning Over Time**

Responses to questions about changes in meaning since beginning as a genetic counselor yielded five domains: Deemphasized individuality, General maturation, Equanimity, Help takes many forms, and Miscellaneous.

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

Many counselors said their sense of *meaning* has changed as they have come to recognize their personal limitations and/or appreciate the importance of being patient-focused.

Some described becoming less driven by 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 10 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.

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!

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

A number of individuals identified the influences of simply maturing over time:

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

*Domain 3: Equanimity (n=8)*

Several counselors expressed that they have developed increased mental calmness as a direct result of difficult and/or complicated patient contexts:

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 having realized over time that genetic counseling is more than giving information or providing support; different people may indeed have different needs.

*Domain 5: Miscellaneous (n=5)*

Five responses, not otherwise classified, included remarks about losing energy and/or emotional tolerance for one's difficult jobs, and that one's sense of *meaning* has not changed.

**Thematic Differences in Participant Responses**

No strong thematic differences due to counselor demographics were evident, other than a few obvious ones such as participants in a committed relationship and parents, respectively, identifying their partners and children as important sources of *meaning*. There were a few differences due to gender, ethnicity and years of experience, although these are speculative given the small numbers of individuals. Male participants (n=3) tended to give shorter, less detailed responses and required a bit more prompting and/or clarification by the interviewer; they seemed to provide less emotional content, although one stated that genetic counseling has been enjoyable because it has "opened a window to feelings" he did not think he had before. They also said their overall views on *meaning* have changed minimally since beginning work as a genetic counselor (although all three were relatively new to the field).

Among the four participants who identified as an ethnicity other than White/Caucasian, some mentioned cultural background as an important source of *meaning*. Finally, some of the five “seasoned” participants (i.e., > 15 years of experience) mentioned feeling more confident and comfortable with their own belief systems over time. They also tended to describe a greater ability to work through value conflicts with patients due to increased humility and empathy.

## Discussion

This study comprehensively explored the extent to which genetic counselors experience *meaning* and how it has been shaped over time. Major findings are discussed next, followed by study strengths and limitations, training and practice implications, and research suggestions.

### Definitions of a Meaningful Life

Overall, participants defined a personal sense of *meaning* as a delicate balance between outward expression of satisfying relationships and inward experience of fulfillment and self-realization. Most spoke of their personal relationships as being the most important things in their lives; moreover, providing service to loved ones affords them a great sense of fulfillment and satisfaction. Others spoke more globally of helping others by improving the world around them.

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

Participants identified various sources that have helped shape their definition of *meaning* over time (i.e., important people, events, and contexts). By far the most prevalent influences were “Health/illness/loss” and “Religious/spiritual contexts.” Although their prevalence likely was due to specific interview prompts, this was frequently the portion of the interview in which individuals became noticeably emotional and increasingly self-reflective. Personal health struggles dramatically impacted counselors’ *meaning*, often in the form of increased empathy. Similarly, witnessing others’ health concerns (i.e., family members, friends, and patients) changed the way many participants view health, purpose and *meaning*. A handful had not experienced or witnessed much loss in their lives and referenced their lack of health issues as shaping their sense of *meaning* in the form of increased gratitude or appreciation.

Regarding religious/spiritual contexts, over half of the sample noted their formal religious backgrounds and/or current practice are central to their *meaning* and purpose. Some participants described unpleasant experiences, which contributed to their denouncing or moving away from formal religious practice altogether. For some, either positive or negative experiences with organized religion led to them to find a deeper

sense of *meaning* within broader spiritual beliefs and practices. These results are fairly consistent with previous findings that a 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 they are also “significantly less likely to believe in god, attend religious services, pray and believe in an afterlife” (Cragun et al., p. 551).

Personal relationships were also significant sources of influence on the counselors’ definition of *meaning*. Sources included respected family members, friends, broader cultural groups, and professional relationships with 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.

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

Virtually everyone emphasized opportunities to help patients as the primary context that allows them to experience deep *meaning*. The majority identified personally meaningful contexts in which they can offer emotional support to patients (e.g., through listening, caring), and those in which they can educate their patients by imparting information (e.g., about disease etiology and risk). Most said they experience *meaning* within their work when they are able to balance support and education, and some stressed the invigorating intellectual challenge of mastering a complex science and tailoring counseling to each patient’s unique needs.

Participants commonly noted that exposure to patients’ and families’ resilience in the face of illness and adversity significantly contributes to their personal sense of *meaning*, most often by strengthening their empathy. Patient experiences also vicariously spark counselors’ self-reflection about how they might deal with similar health situations. Of note, some individuals also expressed that *meaning* feels most present (and/or fulfilling) when they receive direct expressions of gratitude from their patients; patient gratitude allows them to feel successful and validated in their intentions to help others. Relatedly, some described occurrences of self-doubt or frustration when they have felt patients do not appreciate their efforts. “Negative” experiences can be powerful opportunities vis a vis *meaning*. Indeed, Resta (2002) writes that, “A tough lesson for me to learn has been that difficult patients, awful counseling sessions, and awkward encounters offer the best opportunities for professional growth and development... Growth, for me, has most often come from angry, demanding, arrogant patients who did their best to belittle my skills and

knowledge...” (p. 19–20). The findings suggest genetic counselors derive a great deal of *meaning* from their clinical work, with *meaning* commonly revolving around their core motivation to help others in need. They further suggest the genetic counseling profession affords a diverse array of contexts in which to experience, strengthen, and express a personal sense of *meaning* in one’s work.

### Challenges to *Meaning* Experienced Within Genetic Counseling Practice

A majority of the sample identified conflicts between their personal values and those of their patients as a major source of challenge to their experience of *meaning*. As an example, a number of counselors 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. Value conflicts have been shown to comprise prevalent challenges for genetic counselors (cf., Bower et al. 2002; Gschmeidler and Flatscher-Thoeni 2013). When faced with a value conflict, participants tended to resolve it by reminding themselves to appreciate their patients’ individual differences, strengthening their own empathy, and working to support patient autonomy whether or not they agreed with the patients’ decisions. Their strategies are consistent with White’s (1997, 1998) genetic counseling decision making model. White asserts that good decision making occurs when genetic counselors facilitate a dialogue in which the counselor provides relevant information, “introduces different perspectives as appropriate, and thoroughly explore clients’ values and choices with them” (1997, p. 305). Moreover, genetic counselors “...may also question or challenge clients’ views that they perceive to be poorly reasoned, misguided, or perhaps ethically questionable” (1997, p. 305).

Other prevalent challenges to *meaning* centered on genetic counselors’ general discomfort with the pain, loss, or suffering of patients and their families. Some appeared to have reconciled with the reality that life is unfair, while others expressed a certain degree of helplessness and, in a few cases, hopelessness, regarding their perceived inability to serve others in their time of need. Relatedly, some counselors provided examples of competing obligations (e.g., maintaining a work/personal life balance), as well as limited resources as specific challenges to their views on *meaning*.

### Changes in *Meaning* Over Time

Participants commonly noted their views on *meaning* have shifted over time. Overall, they became less “self-focused” through their work and gained increasing awareness of their limitations and their helping potential. Some described increased humility derived, for example, from working with patients who live with much greater challenges than they have

personally experienced. For others, *meaning* has shifted through an enhanced appreciation for the value of relationships as opposed to an exclusive focus on the science/technical aspects of the work. Some participants believed they have simply matured over the years and thus have a better understanding of life’s nuances. Finally, some believed they have strengthened in their abilities to remain mentally calm during stressful situations and recognize help can take many different forms. The counselors generally considered changes in their definitions of *meaning* as positive, although a few noted some disillusionment with the profession. Education and practice around self-reflection and acceptance early in one’s training, as well as throughout one’s career, may help to mitigate negative effects on counselors (e.g., compassion fatigue and burnout).

## Connection of Findings to Theory and to Prior Genetic Counseling Research

### An Existential Foundation

Frankl (1984) 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. He 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 through one’s work or deeds, interpersonal encounters, and/or one’s attitude regarding unavoidable suffering. Consistent with existential theory, participants said they experience profound *meaning* by helping their patients; they identified the importance of interpersonal connections; and they noted their introspection about personal and professional experiences of suffering and related resilience which they have observed in the face of adversity has helped to provide *meaning* to their lives.

Consistent with Yalom’s (1980, 2002, 2008) ultimate existential concerns (*death, freedom, isolation, and meaninglessness*), some participants expressed awareness of their finite time on earth. Consequently, they felt motivated to make the best of their time by working to make the world a better place and also to confront (although often vicariously) their own sense of mortality prompted by the nature of their work. No one explicitly described fear of *isolation*, but the strong emphasis on relationships indicates many feel their personal *meaning* is unfulfilled in the absence of interpersonal connections. Participants also noted they most frequently draw *meaning* from their clinical work when they are able to help patients feel empowered (*freedom*).

The concept of *meaning* served as the foundational basis for this investigation, and thus Yalom’s *meaninglessness* (and one’s responses to this existential “truth”) is implied in virtually every participant response. Yalom (2008) notes working as a therapist and sharing in a patient’s *meaning* is both a

privilege and a way to achieve personal *meaning*. Participants consistently demonstrated this sentiment, noting they experienced enhanced *meaning* when they moved beyond simply helping others to also receiving their own benefits in the form of vicarious lessons, increased empathy, validation through gratitude, intellectual challenge, and resiliency.

### Genetic Counseling Literature

The present findings are highly congruent with studies of genetic counselor professional development. Zahm et al. (2015) found genetic counselors experience intense and profound lessons from their direct interactions with patients (often based on the patients' suffering and related resilience). They also found counselors call upon their personal lives to inform their clinical practice, 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 the present study identified poignant experiences with patients as often as personal experiences with family members and friends as informing their values and their clinical work.

Miranda et al. (2015) found master genetic counselors have deep levels of curiosity and value life-long learning, are authentic in their practice, and incorporate their personality into their counseling style. The present sample similarly spoke about the importance of intellectual stimulation and a quest for knowledge, and a number described how their sense of *meaning* has strengthened as they have learned to integrate their own personal qualities with their professional skills, and thus practice with authenticity. Runyon et al. (2010) similarly found genetic counselors develop a synergistic relationship between their personal and professional experiences over time, and they learn how to let go of control (e.g., by managing personal values/biases/opinions, accepting others' viewpoints, and accepting that some matters are uncontrollable). In the present study, a number of participants spoke of having a strengthened sense of *meaning* when they come to terms with letting go of control.

Pirzadeh and colleagues (2007) found genetic counselors strongly value benevolence and universalism, which seem to represent a self-transcendence (concern for others). These values were prevalent in the present sample's descriptions of *meaning*. Finally, the present results are congruent with McCarthy Veach and colleagues' (2002, 2012) "Defining Moments" essays. Those narratives describe personal and professional catalysts that foster "empathy, authenticity, honesty, self-awareness, resiliency, compassion, connection, courage, and commitment" (McCarthy Veach and LeRoy 2012, p. 166). Many of the present counselors named similar qualities as integral to their development and experience of *meaning* within their practice.

### Study Strengths and Limitations

Strengths of this study include that it is grounded in well-established existential theory. The findings provide insight into genetic counselors' beliefs and values prior to entering the field and changes in their experiences of *meaning* over time. The sample appears to be representative of the genetic counselor population and includes a wide range of experience levels, practice specialties, and geographic regions.

Limitations of the study include that qualitative data are not intended to be generalized to the population of interest. The interview questions were abstract, resulting in a number of interviewees mentioning they were somewhat confusing. The first author attempted to mitigate potential confusion by emailing the questions to participants ahead of time. Participants varied however in their preview of the questions; several did not preview them, while others wrote down responses and referenced them during parts of the interview. Additionally, while their demographics appear largely representative of the genetic counselor population, very few participants self-identified as males and/or non-White/Caucasian. Greater inclusion of their voices is important to deepen understanding of the construct of *meaning*. Finally, participants may differ from non-participants in unknown ways (e.g., self-reflection ability).

### Practice and Training Implications

The present results illuminate nuances inherent to the life and work of a genetic counselor. They suggest the importance of individuals embracing experiences in ways that support their personal aspirations, enhance clinical work, and ultimately support the general tenets of the profession. We postulate that intentional, focused reflection upon issues of *meaning* may mitigate risk for burnout, help counselors cope with compassion fatigue, strengthen their career satisfaction, and ultimately enhance service provision. Indeed, a number of participants thanked the interviewer for engaging with them in a discussion based in the deep, heartfelt experiences they often keep private. Several said they had not yet had an opportunity to share their personal beliefs and values with others in their field. Thus it is important to create accepting environments for genetic counselors to process personal attributes as they relate to their work.

Participants also expressed appreciation for the connections they made over the course of the interview between events in their personal lives and their clinical work. These findings support the need for routine exploration of intersections between one's personal and professional lives. Clinical supervision offers students a venue in which to experience and engage with *meaning* in their practice. Supervisors could foster this activity by inquiring about the ways in which students define *meaning* and how it has evolved. Similarly, a number

of participants emphasized how central their genetic counseling colleagues were to their experience and expression of *meaning*. Thus peer supervision may provide opportunities to explore and process issues of *meaning* as they arise in one's clinical work, to receive support and advice from peers, and to generally meet one's psychosocial needs (Middleton et al. 2007; Zahm et al. 2008). Participation in supervision and mentoring relationships across the professional lifespan may promote exploration of *meaning* and mitigate potential negative effects of repeated engagement with loss and suffering (Injeyan et al. 2011; Lee et al. 2014; Udipi et al. 2008).

Finally, graduate and continuing education should articulate the benefits of consistent self-reflective practice and ongoing exploration of one's views on *meaning*. Activities could be designed to engage students and genetic counselors in discussions of how their views on *meaning* within their clinical work may evolve as they practice. Clinical vignettes may help them identify and navigate their personal sense of *meaning* while working with patients, coworkers, and supervisors/supervisees, and illustrate the benefits of self-reflection (Zahm 2010).

### Research Recommendations

Additional research is needed to deepen understanding of experiences of *meaning* within the practice of genetic counseling. Quantitative studies would help to establish generalizability of the present findings. Use of standardized measures would yield baseline data regarding how genetic counselors generally define a meaningful life for themselves and provide a point of contrast for individual counselors [cf. The Meaning in Life Questionnaire (Steger et al. 2006), The Existential Meaning Scale (Lyon and Younger 2005), and The Spiritual Meaning Scale (Mascaro et al. 2004)]. Longitudinal studies would yield information about shifts in beliefs and experiences of *meaning* in genetic counselor development. Quantitative methods would also allow investigators to determine the relative contributions of individual and cultural variables (e.g., age, race/ethnicity, genetic counseling specialty, experience level, career satisfaction) and major personal and professional life events to one's sense of *meaning*. Given the self-selected nature of the sample, it is unknown whether participants differed from non-participants in their experience and expression of meaning. Studies of individuals who left the profession or intentionally shifted to non-patient care positions would provide insights into how they could or could not derive *meaning* from their patient work. Future investigations should also include genetic counselors who have only worked in non-clinical positions in order to assess whether there are discernible differences in their experiences of *meaning*. Researchers could explore whether non-clinical services provide genetic counselors with similar experiences of meaning derived from clinical practice (e.g., development of empathy, validation

through gratitude, etc.). Finally, the current study focused on genetic counselors' perceptions of how they develop, experience and express *meaning* in their work. It remains unknown how they actually implement their insights in their work. Studies of genetic counseling sessions will help to answer this question.

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### Compliance with Ethical Standards

**Conflict of Interest** David Wells, Patricia McCarthy Veach, Meredith A. Martyr, and Bonnie LeRoy declare they have no conflict of interest.

**Human Studies and Informed Consent** All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000.

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

## Appendix

### Interview Questions

- 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?

## References

- Abrams, L. J., & Kessler, S. (2002). The inner world of the genetic counselor. *Journal of Genetic Counseling, 11*, 5–17.
- Biesecker, B. B. (2001). Goals of genetic counseling. *Clinical Genetics, 60*, 323–330.
- Bjork, J. P., & Thurman, J. W. (2007). Negative life events, patterns of positive and negative religious coping, and psychological functioning. *Journal for the Scientific Study of Religion, 46*(2), 159–167.
- Bower, M. A., McCarthy Veach, P., Bartels, D. M., & LeRoy, B. S. (2002). A survey of genetic counselors' strategies for addressing ethical and professional challenges in practice. *Journal of Genetic Counseling, 11*, 163–186.
- Cragun, R. T., Wotanski, A. R., Myers, M. F., & Cragun, D. L. (2009). Genetic counselors' religiosity and spirituality: are genetic counselors different from the general population? *Journal of Genetic Counseling, 18*, 551–566.
- Farber, B. A., & Heifetz, L. J. (1981). The satisfactions and stresses of psychotherapeutic work: a factor analytic study. *Professional Psychology, 12*(5), 621–630.
- Frankl, V. E. (1984). *Man's search for meaning*. New York: Washington Square Press.
- Gschmeidler, B., & Flatscher-Thoeni, M. (2013). Ethical and professional challenges of genetic counseling – the case of Austria. *Journal of Genetic Counseling, 22*, 741–752.
- Hill, C. E. (Ed.). (2012). *Consensual qualitative research: A practical resource for investigating social science phenomena*. Washington, DC: American Psychological Association.
- Hill, C. E., Thompson, B. J., & Nutt-Williams, E. N. (1997). A guide to conducting consensual qualitative research. *Journal of Counseling Psychology, 25*, 517–572.
- Hill, C. E., Knox, S., Thompson, B. J., Williams, E. N., Hess, S. A., & Ladany, N. (2005). Consensual qualitative research: an update. *Journal of Counseling Psychology, 52*, 196–205.
- Injeyan, M. C., Shuman, C., Shugar, A., Chitayat, D., Eshetu, G., & Kaiser, A. (2011). Personality traits associated with genetic counselor compassion fatigue: the roles of dispositional optimism and locus of control. *Journal of Genetic Counseling, 20*, 526–540.
- Kessler, S. (1992). Psychological aspects of genetic counseling. VIII. Suffering and countertransference. *Journal of Genetic Counseling, 1*, 303–308.
- Lee, W., McCarthy Veach, P., MacFarlane, I. M., & LeRoy, B. S. (2014). Who is at risk for compassion fatigue? An investigation of genetic counselor demographics, anxiety, compassion satisfaction, and burnout. *Journal of Genetic Counseling*. doi:10.1007/s10897-014-9716-5.
- Lyon, D. E., & Younger, J. (2005). Development and preliminary evaluation of the existential meaning scale. *Journal of Holistic Nursing, 23*, 54–65.
- Mascaro, N., Rosen, D. H., & Morey, L. C. (2004). The development, construct validity, and clinical utility of the spiritual meaning scale. *Personality and Individual Differences, 37*, 845–860.
- McCarthy Veach, P., & LeRoy, B. (2012). Defining moments in genetic counselor professional development: one decade later. *Journal of Genetic Counseling, 21*, 162–166.
- McCarthy Veach, P., Bartels, D. M., & LeRoy, B. S. (2002). Defining moments: catalysts for professional development. *Journal of Genetic Counseling, 11*, 277–280.
- McCarthy Veach, P., Bartels, D. M., & LeRoy, B. S. (2007). Coming full circle: a Reciprocal-Engagement Model of genetic counseling practice. *Journal of Genetic Counseling, 16*, 713–728.
- Middleton, A., Wiles, V., Kershaw, A., Everest, S., Downing, S., Burton, H., ..., & Landy, A. (2007). Reflections on the experience of counseling supervision by a team of genetic counselors from the UK. *Journal of Genetic Counseling, 16*, 143–155.
- Miranda, C., McCarthy Veach, P., Martyr, M. A., & LeRoy, B. S. (2015). Portrait of the master genetic counselor clinician: a qualitative investigation of expertise in genetic counseling. *Journal of Genetic Counseling*. doi:10.1007/s10897-015-9863-3.
- Morse, J. M. (2000). Determining sample size. *Qualitative Health Research, 10*, 3–5.
- National Society of Genetic Counselors (NSGC) (2012). Professional status survey: Executive summary; [www.nsgc.org](http://www.nsgc.org).
- Pargament, K. I. (1997). *The psychology of religion and coping: Theory, research, practice* (1st ed.). New York: The Guilford Press.
- Pirzadeh, S. M., McCarthy Veach, P., Bartels, D. M., Kao, J., & LeRoy, B. S. (2007). A national survey of genetic counselors' personal values. *Journal of Genetic Counseling, 16*, 763–773.
- Resta, R. (2002). Commentary on 'the inner world of the genetic counselor: the unexamined counseling life. *Journal of Genetic Counseling, 11*, 19–23.
- Runyon, M., Zahm, K. W., McCarthy Veach, P., MacFarlane, I. M., & LeRoy, B. S. (2010). What do genetic counselors learn on the job? A qualitative assessment of professional development outcomes. *Journal of Genetic Counseling, 19*, 371–386.
- Sartre, J-P. (2007). *Existentialism is a humanism*. (C. Macomber, Trans.). New Haven, CT: Yale University Press. (Original work published 1946).
- Schwartz, S. H. (1992). Universals in the content and structure of values: Theoretical advances and empirical tests in 20 countries. In M. Zanna (Ed.), *Advances in experimental social psychology* (pp. 1–65). Boston: Academic.
- Schwartz, M. D., Hughes, C., Roth, J., Main, D., Peshkin, B. N., Isaacs, C., & Lerman, C. (2000). Spiritual faith and genetic testing decisions among high-risk breast cancer probands. *Cancer Epidemiology, Biomarkers & Prevention: A publication of the American*

- Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology*, 9(4), 381–385.
- Steger, M. F., Frazier, P., Oishi, S., & Kaler, M. (2006). The meaning in life questionnaire: assessing the presence of and search for meaning in life. *Journal of Counseling Psychology*, 53(1), 80–93.
- Udipi, S., McCarthy Veach, P., Kao, J., & LeRoy, B. S. (2008). The psychic costs of empathic engagement: personal and demographic predictors of genetic counselor compassion fatigue. *Journal of Genetic Counseling*, 17, 459–471.
- White, M. T. (1997). “Respect for autonomy” in genetic counseling: an analysis and a proposal. *Journal of Genetic Counseling*, 6, 297–313.
- White, M. T. (1998). Decision-making through dialogue: reconfiguring autonomy in genetic counseling. *Theoretical Medicine and Bioethics*, 19, 5–19.
- White, M. T. (2006). Religious and spiritual concerns in genetic testing and decision making: an introduction for pastoral and genetic counselors. *The Journal of Clinical Ethics*, 17(2), 158–167.
- Yalom, I. D. (1980). *Existential psychotherapy*. New York: Basic Books.
- Yalom, I. D. (1989). *Love’s executioner*. New York: Basic Books.
- Yalom, I. D. (2002). *The gift of therapy*. New York: Harper Collins.
- Yalom, I. D. (2008). *Staring at the sun: Overcoming the terror of death*. San Francisco: Jossey Bass.
- Zahm, K. W. (2010). Professional development: Reflective genetic counseling practice. In B. S. LeRoy, P. McCarthy Veach, & D. M. Bartels (Eds.), *Genetic counseling practice: Advanced concepts and skills* (pp. 353–380). Hoboken: Wiley Blackwell.
- Zahm, K. W., McCarthy Veach, P., & LeRoy, B. (2008). An investigation of genetic counselor experiences in peer group supervision. *Journal of Genetic Counseling*, 17, 220–233.
- Zahm, K. W., McCarthy Veach, P., Martyr, M. A., & LeRoy, B. S. (2015). From novice to seasoned practitioner: A qualitative investigation of genetic counselor professional development. *Journal of Genetic Counseling*. doi:10.1007/s10897-015-9900-2.
- Zinnbauer, B. J., Pargament, K. I., Cole, B., Rye, M. S., Butfer, E. M., Belavich, T. G., ..., & Kadar, J. L. (1997). Religion and spirituality: unfuzzifying the fuzzy. *Journal for the Scientific Study of Religion*, 16(4), 549–564.