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INFLUENCE OF GENETIC COUNSELOR PERSONAL OR FAMILY MEDICAL HISTORY ON GENETIC COUNSELING SPECIALIZATION AND PRACTICE

Kaitlyn K. Amos MS

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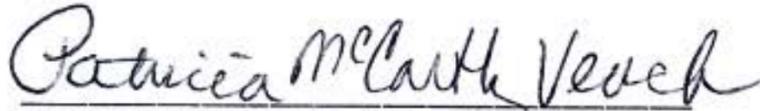
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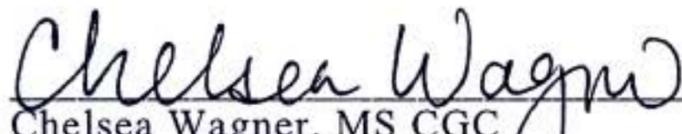
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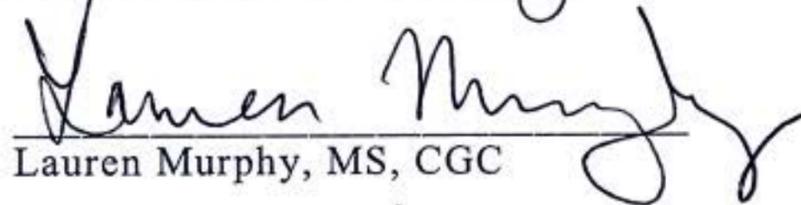
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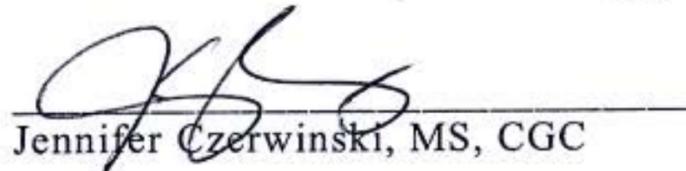
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ON GENETIC COUNSELING SPECIALIZATION AND PRACTICE

A

THESIS

Presented to the Faculty of

The University of Texas

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for the Degree of

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by

Kaitlyn Kelly Amos

Houston, Texas

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INFLUENCE OF GENETIC COUNSELOR PERSONAL OR FAMILY MEDICAL HISTORY ON GENETIC COUNSELING SPECIALIATION AND PRACTICE

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A personal or family medical history inherently becomes part of a genetic counselor's life story. Yet the degree to which a counselor's experience influences his or her specialty choice and their psychosocial practice is unexplored. A medical diagnosis may foster a counselor's capacity for greater empathy, understanding and rapport-building self-disclosure. Conversely, it could lead to interruptive countertransference, compassion fatigue, and eventually burnout. However, research has not specifically investigated this intersection. Therefore, the aim of this study was to explore the impact of a genetic counselor's personal or family medical history on his or her choice of practice area, as well as the perceived impact on their psychosocial work within sessions. Members of the National Society of Genetic Counselors were recruited to complete an anonymous online survey sent via a research recruitment email. Of the 69 survey respondents that met inclusion criteria, 23 volunteered for and completed subsequent telephone interviews. Open-ended responses to the interview questions were transcribed and analyzed by the principal investigator using inductive analysis. Interview participants were more likely to be attracted to a specialty possessing overlap with their medical history ($n=15$) and attributed many of their psychosocial strengths to their personal and/or family medical experience, such as increased empathy and a more expansive scope of how they cared for the patient ($n=21$). However, many counselors indicated that their medical histories did not frequently influence their practice, with 14 participants initially denying or downplaying use of self-disclosure. Contradictory to their assertions, the majority of participants ($n=19$) gave at least one example of self-disclosure, whether indirect, prompted, support-motivated, or direct. Importantly, 20 participants named or illustrated countertransference. This study highlights that while medical histories can become a positive asset in a genetic counselor's care for patients, they require a counselor's diligent attentiveness to honest self-reflection.

Table of Contents

Approval Sheet.....	i
Title Page.....	ii
Acknowledgements.....	iii
Abstract.....	iv
Table of Contents.....	v
List of Illustrations.....	vi
List of Tables.....	vii
Introduction.....	1
Methods.....	5
Results.....	8
Discussion.....	25
Conclusions.....	32
Appendix.....	34
Bibliography.....	46
Vita.....	49

List of Illustrations

Figure 1. Medical History Impact on Current Specialty Choice.....15

Figure 2. Frequency of Psychosocial Influence.....19

List of Tables

Table 1. Respondent Demographics.....	9
Table 2. Medical History Domains, Codes and Quotes.....	10
Table 3. Novice vs. Experienced Genetic Counselors	14
Table 4. Specialty Choice.....	16
Table 5. Psychosocial Influence.....	20

INTRODUCTION

Specialty Motivation

Factors that motivate individuals to choose a career within the helping professions have been widely studied. From personality traits to core values to circumstantial events, intrinsic and extrinsic incentives like financial gain, vocational prestige, altruism and family of origin have been identified as factors influencing different helping roles, particularly in the fields of medicine, nursing, and psychology (1-3). In 2005, Lega and colleagues surveyed 235 genetic counseling students' motivations toward the profession. The survey found that the majority of participants noted intellectual attraction, affinity for science, helping others, and confidence in career fit as the most important factors in drawing them to the field (4). This study was expanded in 2020, surveying 430 students enrolled in 2018-2019; this study found that genetic counseling students were additionally motivated by prestige of the field, expected income and a relatively condensed training program (2 years) (5). The 2005 study additionally highlighted that while one third of the respondents had family histories of genetic conditions, 62% felt that such family histories had no influence on their desire to pursue genetic counseling (4). This finding is surprising, since research has suggested that family dynamics can have bearing on the career course for helping professionals (6). For example, children with siblings with intellectual disabilities demonstrated a greater degree of altruism, and were therefore motivated to pursue a career within a helping profession such as special education (7). In a 2011 prospective study of adult siblings of individuals with intellectual disabilities, researchers found that factors such as being an older sibling, having only one sibling, and relational closeness were positive predictors of general altruistic behavior as well as pursuit of helping professions in female siblings (8). Similar to Lega et al., one quarter of participants in Stoddard and colleagues' expanded, 2020 study had family histories of genetic conditions. However, the reported impact of family histories from these participants ranged from little or no influence, to a great deal of influence, with an average response of some influence (5). Stoddard and

colleagues suspect such results reflect how family medical histories affect individual career motivations differently.

Psychology literature expands on familial influence over career choice. A 2007 qualitative study purported that many clinical therapists do not recognize their true vocational motivation without time, professional maturity and reflection, specifically by way of personal psychotherapy (9). Barnett described two themes that emerged from her exploratory interviews with clinical psychologists; most of her sample had experienced a type of loss or suffering during childhood or adolescent years, and narcissistic (or unmet) childhood needs led to a therapist's desire to model a more ideal authoritative figure. She connected these themes to dynamics existent within the therapist's original family (9). Barnett's exploration parallels DiCaccavo's work which suggested that a large percentage of therapists were prematurely thrust into caregiving roles as children, or experienced childhood neglect and hardship, and thus were more likely to end up in caregiving roles (6).

Psychosocial Practice

Concepts are presented in the seminal psychosocial training texts about the impact the genetic counselor can have on a patient (10, 11). These texts lay a foundation for genetic counselors' education of concepts like attunement, empathy, self-disclosure, compassion fatigue, burnout, and countertransference, while a matured portrait of these ideas are embodied in another study profiling the 'master genetic counselor' (12). Miranda and colleagues detail how these fundamental, yet abstract, psychosocial concepts develop over time through the nuances of a genetic counselor's continued personal and professional growth (12).

From start to finish, however, it is agreed that the triggers and manifestations of experiences like countertransference are inevitably part of the course of professional genetic counselors (13, 14). Countertransference has been categorized as the unconscious but often-occurring reactions to dynamics within a client-therapist relationship, frequently born out of unresolved personal problems harbored by the therapist (13, 15). A 2017 meta-analysis of countertransference identified five common triggers for

genetic counselors: resemblance to a patient, dealing with an angry patient, the responsibility to disclose bad news, unexpected patient reactions, and medical similarity. Reeder and colleagues found that situational triggers could cause a counselor to become more self-engaged than patient-focused, to emotionally project, to over-identify, and to encounter other disruptive consequences that required management (2017). While countertransference inescapably exists, this phenomenon in the life of a counselor can simultaneously lead to an increase in compassion and empathy for a patient (16). Personal experience, whether painful or joyful, can allow for an expanded understanding of a patient's or client's context, and thus deepen a counselor's ability to connect, support and guide (17).

Wells and colleagues interviewed 68 genetic counselors to understand how they define and create meaning in their lives, and found that 23 noted personal health and loss as a strong source of meaning within their careers, and as influential in directly or indirectly framing the focus of their clinical style (18). Indeed, one of several predictors of a genetic professional's comfort and competency in caring for the grief and loss of their patients stemmed from their personal encounter with loss and subsequent meaning derived from their patient care (19). Henri Nouwen describes the concept of a 'wounded healer,' explaining that a clinician's personal tragedy can lead to a dual experience in which both patient and clinician benefit from a therapeutic relationship (20-22). Zerubavel expanded on this idea, presenting it as a dilemma: personal tragedy can lead to effective and mutual benefit, or it can impair the professional's work (23). Such denial of a clinician's own woundedness can lead to projection, and a dichotomous healed-vs.-broken relational hierarchy (23). Gelso and Hayes emphasize the critical nature of a therapist's role in understanding their own pain prior to patient care (24).

Medical Histories and Practice

Interpersonal psychosocial expressions such as self-disclosure or countertransference are primarily rooted in the genetic counselor's formative life moments (25). Thus personal life experiences have bearing in directing and shaping the professional realm of genetic counseling (26). Furthermore, since the field's inception, there has been an expansion of genetic counseling specialties and

subspecialties, such as cancer genetics and cardiovascular genetics (27, 28). Such expansion suggests that the likelihood that individuals pursuing a vocation in genetic counseling could carry a personal or family history that overlaps with a now-available specialty choice has increased.

Lega and colleagues speculated that their sample of genetic counselors had a higher proportion of individuals with family histories than the general population, but subsequently found that more than half of the participants said this characteristic had little or no influence on their motivation toward the field of genetic counseling (4). A similar survey explored the influence of receiving genetic counseling services on a genetic counselor's career choice, and demonstrated that only 11% of 93 genetic counselors reported impact, and only 7.5% of this sample chose a specialty area because of their personal experience as a patient (25). Contradicting these findings are two series of personal essays, split between 2002 and 2012, discussing the professional turning points and repercussions of pivotal life moments of practicing genetic counselors (29, 30). These defining moments narratives provide insight into the effects of personal life events on specialty choice. In one essay, a genetic counselor ultimately changes her practice area from prenatal clinical work to research, because of her countertransference after having a pregnancy with anomalies (31). The narratives illustrate both overt and subtle ways a genetic counselor's medical history affects his or her interpersonal relationship with patients. They offer anecdotal evidence for the permeation of a personal story into the psychosocial domain, through phenomena such as countertransference, empathy, self-disclosure, compassion fatigue and attunement (16, 29, 30). For example, Keilman talks about the way her daughter's diagnosis both invigorated her clinical preparation and moved head knowledge to heart knowledge, but that she often is still taken by surprise by moments of countertransference (32). A common theme across the individual essays is genetic counselors' willingness to reflect, learn from and apply their experiences to their practice (30). However, these essays do not consistently explore or capture nuanced influence on career trajectory beyond individual case reports (29, 30). Furthermore, while Peters and colleagues' study revealed that counselors who had received genetic counseling services reported little influence on career choice, participants did indicate

that their experience as a patient strengthened areas of psychosocial practice, such as increased empathy, greater attunement, better rapport with patients and more meaningful self-disclosure (25).

Despite ancillary glimpses of how genetic counselors' medical histories intersect their practice, current research does not specifically investigate how these histories influence career specialization or characterize the extent to which a genetic counselor's work with patients is strengthened or impeded. A personal medical diagnosis may foster a counselor's capacity for greater empathy, understanding, and rapport-building self-disclosure (17, 33). Contrarily, it may lead to interruptive countertransference, compassion fatigue, and eventually burnout (31). No matter the influence, it is important to understand how genetic counselors carry their stories into their practice, and how they steward the pain and vulnerable formation stemming from their own encounters with medical diagnoses, both for the care of the patient and the development of their career. Therefore, this study aimed to explore the impact of genetic counselor's personal or medical history on their choice of practice specialty, as well as their psychosocial work within a session.

METHODS

The project was reviewed and approved by the institutional review board at the University of Texas Health Science Center at Houston (HSC-MS-19-0400).

Participants and Procedures

Certified genetic counselors who had a personal and/or family medical history of a genetic condition, major illness, or genetic predisposition were invited to participate in an electronic survey. Additionally, individuals willing to participate in a follow-up phone interview were asked to provide their contact information. The survey link was distributed via an eblast to all members of the National Society of Genetic Counselors (NSGC). The initial invitation was sent in July 2019, and a reminder was sent 2 weeks later.

Survey respondents who indicated willingness to participate in a semi-structured, recorded telephone interview were contacted via email to schedule a time slot. Telephone interviews were conducted and audio-recorded between September-December 2019. They were transcribed verbatim, using Trint software, and were reviewed by the principal investigator. Interviews lasted an average of 25 minutes (Range: 11 minutes to 40 minutes).

Instrumentation

Survey

An electronic survey was created using Qualtrics software (v. July 2019, Qualtrics, Provo, UT). A draft of the survey was piloted with 5 practicing genetic counselors who offered feedback about the survey's content, clarity and organization.

The electronic survey consisted of five parts: (1) inclusion criteria, (2) demographic questions including initial and current, primary and secondary specialties adapted from the 2018 NSGC Professional Status Survey, (3) description of personal history of a genetic/medical condition, major illness or predisposition to a genetic condition and the impact it had on the participant's specialty choice, (4) description of a first, second or third degree relative with history of a genetic/medical condition, major illness or predisposition to a genetic condition and timing of the diagnosis and the impact it had on the participant's specialty choice, and (5) direct patient care impact. Sections that inquired about impact and influence utilized Likert scales for responses (Supplemental Document 1).

Interview

A telephone script for the semi-structured interviews was developed based on review of relevant literature and the authors' clinical and research experience. Eleven, open-ended questions asked about the participant's personal or family medical diagnoses, how the condition/experience influenced their practice specialty choices, and various ways they perceived that the condition/experience influenced their clinical interactions within the psychosocial domain (Supplemental Document II). The interviewees were

asked to provide anecdotal examples for several questions. The interview was piloted with a practicing genetic counselor who offered feedback about the interview questions and information flow.

Data Analysis

Both survey and interview participants were stratified into two groups based on their years of experience as a genetic counselor. The first group, Novice, represented <1 to 4 years in practice, and the second group, Experienced, represented 5 or more years in practice. Ranges for the years of experience were selected based on review of relevant literature and the authors' research experience. Both survey and interview participants were classified within three additional categories based on a personal medical history, a family medical history, or both.

Descriptive statistics, including means, ranges, standard deviations, percentages, and frequencies were calculated for survey items using Stata v.13.1 (StataCorp, College Station, TX). Mann-Whitney-U test, t-test, and Fisher's exact test were conducted, where appropriate, to examine demographic differences between the interview sample, the survey sample, and the sample of respondents to the 2020 NSGC Professional Status Survey. Perceived impact of personal medical history and/or family medical history was reported and compared as percentages.

Written, open-ended comments on the survey and transcribed, open-ended responses to the semi-structured phone interview questions were analyzed by the principal investigator using inductive analysis. Transcripts were entered into ATLAS.ti qualitative data analysis software version 8.4.4 and were coded for themes. Codes were assigned a label reflecting the underlying concept and organized into conceptually similar groupings. The last author served as data auditor, and independently reviewed six transcripts for coding and grouping consensus. The transcripts were discussed until concordance was achieved. The principal investigator analyzed the remaining transcripts for codes and grouped the codes into themes.

RESULTS

Participant Demographics

Of the 3,400 NSGC members, a total of 139 (4.1%) participants completed at least a portion of the survey. It is unknown how many of the 3,400 NSGC members have a qualifying personal or family history to provide a specific response rate. Sixty-nine respondents met completion and inclusion criteria, and of these, 32 (46%) indicated a willingness to participate in an audio-recorded phone interview. Three individuals were excluded due to their affiliation with the principal investigator's institution, and six could not be reached after multiple attempts. Thus, twenty-three participants were interviewed and included in the interview analysis.

The average age of survey participants was 34 years and the average age of interview participants was 32 years. The majority of participants were female and Caucasian (Table 1). There were 36 Novice genetic counselors (≤ 4 years of experience) who participated in the survey and 33 Experienced genetic counselors (≥ 5 years). There were no significant differences between the demographics of the survey group and the interview group ($p > 0.05$) for age, work setting, time in field, time in current primary and secondary specialty, primary area of practice, and type of medical history. Additionally, the demographics of the survey cohort were consistent with the genetic counseling profession, as reported by the 2020 NSGC Professional Status Surveys, for comparisons of age, work setting, time in field, time in current specialty, and primary area of practice ($p > 0.05$). Both survey and interviewee participants were more likely to report only a family medical history ($> 50\%$), than they were to report only a personal history or a combined (family and personal) medical history (Table 1).

Table 1: Survey and Interview Participant Demographics

Variable	Survey Respondents (n=69)		Interviewees (n=23)	
	<i>n</i>	%	<i>n</i>	%
Gender				
Female	68	99	23	100
Male	1	1		
Ethnicity				
Caucasian	68	99	23	100
Hispanic, Caucasian	1	1		
Current Primary Specialty				
Cancer	18	26		30
Neurology	2	3		9
Pediatrics	8	12		13
Prenatal	14	20		13
General Genetics	3	4		0
Laboratory	6	9		9
Education	6	9		9
Metabolic	1	1		4
Specialty Diseases	2	3		4
Research	5	7		4
Other	4	6		4
Direct Patient Care				
Yes	55	83	23	100
No	11	17	0	0
> 1 Specialty				
Yes	46	67	18	78
No	23	33	5	22
Medical History				
Personal	9	13	3	13
Family	37	54	13	57
Both	23	33	7	30
Age				
Range	23-62		23-51	
Average	34		32	
Years in Field				
Novice (<1 - 4 years)	36	52	11	48
Experienced (5+ years)	33	48	12	52
Mean	8		7	
Range	1-35		1-26	

Analysis of Interviewee Responses

Medical Story

There are three overarching domains within Medical Story: diagnostic experience, emotional formation, and counseling experience. Table 2 contains the domains, associated categories, and illustrative quotations.

Table 2: Medical Story Domains, Categories, and Illustrative Quotations

Domain	Code	Frequency (<i>n</i>)	Illustrative Quotation
Diagnostic Experience	Diagnosis/condition occurred prior to grad school	18	<i>So I found out that they were positive probably in high school.</i>
	GC lived in proximity to, or was relationally very close to individual with diagnosis	13	<i>...and, you know, we grew up together. I mean, we lived across the street from one another...</i>
	Diagnosis was abrupt or induced major life transition	10	<i>And so it is really surprising when my mom, you know called, and said, you know, the test was positive which was pretty shocking for everyone.</i>
	Diagnosis/condition was recent	8	<i>I just had remission documented this past [month].</i>
	GC had more than one family member affected	8	<i>...my dad died of [medical condition] at [age], and my mom actually died of a [medical condition] at [age]. And...I also had a [sibling] who passed away at [age] from complications of a [medical condition].</i>
	GC experienced a misdiagnosis or misinformation	5	<i>...from my personal experience, I feel that like it was not something that was explained extremely well to me.</i>
	GC had genetic counseling	4	<i>So then I pretty immediately booked a genetic counseling appointment for myself...</i>
Emotional Formation	GC was well-acquainted with trauma or severe loss	9	<i>But I think, like, when you get older and you realize how hard they struggled for like medical care, and like how much debt that they carried, just to like kind of keep afloat.</i>
	GC was thrust into premature caregiver role as child,	5	<i>My uncle was about eight years older than me... But my mom...she immediately went and got him and moved him in with</i>

	adolescent or young adult due to family history		<i>us.... So, so he lived with us. And by that time, I was in high school. And he lived with us, you know, my whole rest of my time at home. And then, you know, as I sometimes would help watch him...</i>
	GC had a mentor or an ally that helped them adjust	3	<i>So I think that the nice thing has been like just having - I have a really great boss, and I am able to kind of like decompress with her after those sessions.</i>
Counseling Experience	Encountered resonant situations/parallel between GC & patient lives	16	<i>The interesting thing is that I do kind of see a lot of [medical condition], in general. Just because it's so common.</i>
	GC narrated or demonstrated unresolved parts of personal story or family dynamic	8	<i>...they were very fixated because that side of [my] family is just very fixated on, well, I guess kind of guilt and blame. They always want to know whose fault is.</i>
	GC demonstrated conflict with training	4	<i>I try very, very hard to not disclose, because we're really trained not to do that....</i>
	GC felt survivor's guilt	3	<i>But I think there's like subtle aspects of like being the one in the family, who tests negative, that I now appreciate.</i>
	GC felt increased gratitude for 'not having it as bad' when learning patient's story	2	<i>...And so I think there was a lot of gratitude of like: 'Oh, my gosh.' Like, 'It could've been so much worse.'</i>

Diagnostic Experience

Many of the genetic counselors interviewed ($n=18$) experienced a diagnosis in their personal lives, or in their family's lives, prior to graduate school. Some counselors explained that the diagnosis was abrupt, or induced a major life transition, with some ($n=8$) indicating that the diagnosis was recent (within the last two years). More than half of participants talked about a relational closeness or regional proximity to the affected individual ($n=13$), and several respondents ($n=8$) had more than one family member affected. Four genetic counselors had received genetic counseling, themselves, as patients.

During their interview, several participants also talked about how they, or their family member, had experienced a misdiagnosis or a poor explanation of their condition during the diagnostic journey, and how this experience was frustrating or detrimental.

“I mean, it's what made me interested in genetics, in [specialty], I think. The misinformation. You know, that they were kind of told like, 'Hey, if you do this, everything will be fine.' And I was not fine. And they did what they were supposed to do...”

Emotional Formation

Some genetic counselors told stories that demonstrated an acquaintance with trauma, or severe grief from loss through their medical history ($n=9$), and some narrated or demonstrated unresolved parts of their personal or family medical history at different moments within an interview ($n=8$). Traumatic experience codes were occasionally observed in combination with demonstrations of guilt or uncertainty ($n=3$), as well as deeper appreciation for human complexity ($n=2$) and honesty in loss ($n=2$). Likewise, lack of resolution was observed in combination with observed countertransference in a third of interviews ($n=8$), as well as a few times with judgment ($n=1$), temptation to rank the severity of a patient's diagnosis against their own ($n=1$) and projection ($n=3$). A small group of participants described taking on some sort of caregiving role of the affected family member during childhood or adolescence - a distinctly premature point in their life cycle ($n=5$). Other genetic counselors profiled a scholastic mentor or professional ally who helped them manage or adjust to their medical story ($n=3$).

“I was really trying to get a diagnosis for [family member] because she needed like Social Security disability, and she never wrote on the application that she had [medical] condition because she didn't think she had it. So I needed a diagnosis from a neurologist. And we arranged for that testing, and finally got the diagnosis. And I think [another family member] took her to that appointment, but I was the one to, like, reach out to the doctors... to sort of really figure out how we could get this diagnosis.”

“Yeah. And I, I told my director during our first one-on-one meeting (she was my advisor for the program), and I asked for an hour meeting instead of just a half-hour meeting so I could disclose this to her.”

Counseling Experience

Most genetic counselors ($n=16$) described encountering a patient with whom they situationally resonated, such as a similar age, family structure, or diagnostic experience. These situations were explained to be similar in the contextual structures of the patient’s life and the genetic counselor’s life, rather than similar emotional experiences. Several participants ($n=3$) explained that they felt survivor’s guilt because of their medical history, whether in direct response to a patient or residually from their relationship with their own affected family member, a sentiment that carried over into practice. Others described an increased sense of gratitude for their own journey, as compared to their patient’s journey ($n=2$). Several genetic counselors demonstrated or narrated conflict with their training, mostly as it pertained to their use of self-disclosure ($n=4$).

“I feel like it's part of the genetic counseling training programs. We kind of get it beaten into our head that like, 'don't self-disclose. In self-disclosure, you're bringing yourself into the session and you're taking the focus away from the patient,' and 'Self-disclosure is very rare, very select circumstances, and is bad.' And so it's a little hard...”

Apparent Thematic Differences

Experienced genetic counselors discussed more experience with an abrupt/major life transition from their medical story ($n=8$) than novice genetic counselors ($n=2$). Novice genetic counselors gave more examples of being placed into premature caregiving roles ($n=4$) than experienced genetic counselors ($n=1$), (Table 3).

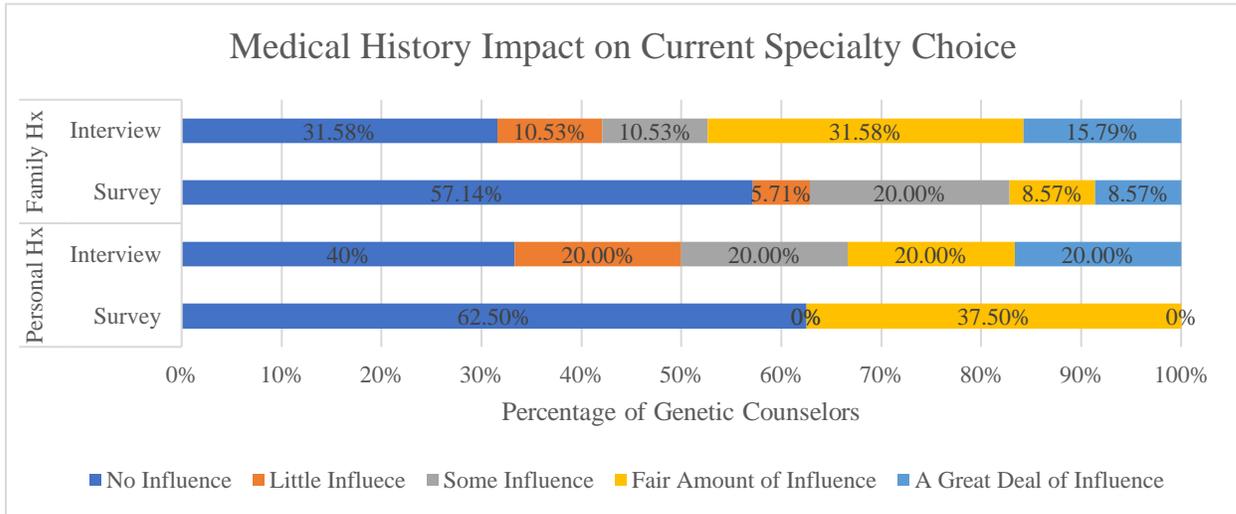
Table 3: Thematic Differences in Novice vs. Experienced Genetic Counselor Responses

Codes	Novice (n=11)	Experienced (n=12)
Medical Story/Experience		
Abrupt/Major Life Transition	n=2	n=8
Premature Care-giver Role	n=4	n=1
Specialty Influence		
Passion	n=7	n=10
Psychosocial Influence		
Positive Appraisal	n=4	n=9
Empathy	n=7	n=10
Emotional Scope	n=5	n=9
Fuller Exploration	n=4	n=7
Support/Advocate	n=6	n=8
Judgement	n=5	n=2

Specialty Choice***Reported Impact***

On the electronic survey, participants were asked to indicate how much their medical history, personal and/or family, impacted their choice of specialty. While more interview participants reported that their story had a greater impact on their specialty choice than survey participants, there was no statistically significant difference between the survey participants and interview participants for personal medical history ($p=0.221$) or family medical history ($p=0.061$), (two-sample t test). Interview participants were relatively split on whether their personal history had little to no influence (41%) or a fair amount to a great deal of influence (47%) on specialty choice (Figure 1).

Figure 1: Medical History Impact on Current Specialty Choice



Overall, most interview participants reported an attraction to the field in general as well as a specialty similar to their story, but many also had circumstances that dictated their specialty choice. There are four overarching domains within Specialty Choice: attraction, aversion, other specialty influence and field-related movement. Table 4 contains the domains, associated categories, and illustrative quotations.

Table 4: Specialty Choice Domains, Categories, and Illustrative Quotations

Specialty Choice			
Domain	Code	Frequency (n)	Response
Attraction	Attraction to a similar specialty/research as medical history	15	<i>And I wanted to be able to kind of work with those families, as I could truly, I could truly appreciate what they were going through...</i>
	GC communicated increased passion about specialty/subject, based on medical history	10	<i>And I wanted to be able to like not only talk to parents about how to like move forward, to like normalize things, or help explain things in the context of like genetics and how some things we can control and some things we can't.</i>
	GC experienced a passive recognition of attraction to their similar specialty	4	<i>...I honestly didn't recognize that... it's not until you are exposed to it [specialty that overlaps with medical history] that you realize the difference [in interest]</i>
Alternative Influences	Circumstantially/opportunity dictated specialty	16	<i>Yeah, I was a prenatal counselor to start. And that's because, you know, the only thing back then was peds and prenatal.</i>
	Personal/intellectual preference	16	<i>I thought my primary interest would be cancer because of my family history. However, I was not intellectually simulated by the specialty and much preferred prenatal.</i>
	GC had a formative, professional exposure that played a part or directed their specialty choice	7	<i>I thought I wanted to be a GC working clinical research, probably because that was like the main GC that I was exposed to...</i>
Field-Related Movement	GC described motivation toward general field	10	<i>...having my health care at a [type of] clinic in a genetics clinic is what first introduced me to genetic counseling in general.</i>
	GC medical history prompted a change of specialty	8	<i>I quit that [job] I asked to be removed from it over those concerns. That part hit way too close to home...</i>
Aversion	Medical history motivated GC away from specialty	3	<i>...one patient in particular that just reminded me a lot of my [family member]...But for me, I sort of wanted to run from that.</i>

Attraction: Motivation Toward or Away from Specialty, Because of Medical History

During the interview, when asked how medical history affected their choice of specialty, many counselors indicated it made them more attracted to a similar specialty or research focus ($n=15$), while only a few indicated their medical history prompted them to avoid or leave certain specialties because of negative associations ($n=3$). Reasons for attraction included a desire to make meaning of or find fulfillment in their story through their practice, a desire to redeem the misinformation they or a family member had experienced (which some described as “paying it forward”), or because they felt equipped with a greater familiarity or depth of specialized knowledge from their experience. A few genetic counselors ($n=4$) also expressed a passive recognition of attraction to their specialty, based on their medical history, because of belated exposure to that specialty.

“Cancer, for me, felt like a better fit because of the depth of knowledge I have, for better or worse, about the whole cancer experience from start to finish...But you know, like I've done these things, and I've had the personal experience of just about every [adjective] treatment we have for cancer...and I felt like I had this deep knowledge of what that is like, that I could hopefully put to good use.”

Additional Observations: Other Specialty Influence

Most genetic counselors ($n=16$) depicted how a situational circumstance, job opportunity or lack thereof, or personal/intellectual preference directed their choice of specialization. Others described a formative experience, such as receiving genetic counseling or a shadowing opportunity before training, that informed their specialty choice ($n=7$). Sometimes, circumstances carried greater weight in a vocational decision-making process for the genetic counselor than their sense of attraction to a specialty based on their medical history (e.g., a need to be in a specific location) ($n=9$). Other circumstances, such as absence of an existing specialty, dictated a counselor's choice.

“So actually to the point, when I interviewed for graduate school and they asked, you know, if I had any particular interests, my answer in my grad school interviews, was that I wanted to establish an [type of] genetic counseling specialty. That was kind of a professional goal of mine. So while it didn't influence at all my choice to be a [type of specialty] genetic counselor, that is still something that is very much on my mind, like a potential, eventual specialty direction...”

Additional Observations: Field-Related Movement

Genetic counselors were specifically asked to describe their medical story's impact on their choice of specialty. However, just under half of respondents ($n=10$) described their attraction toward the field of genetic counseling more than to a specific specialty. Some genetic counselors did narrate a change in specialty – more often toward a specialty similar to their story ($n=6$) than away from it ($n=2$), though some specialty changes were influenced by circumstantial shifts related to events in the genetic counselor's life cycle.

“So, I think that attracted me to genetic counseling. And then other, other things in my personal life. You know, nothing dramatic or significant, but I dealt with some very minor health issues in high school and I kept getting misdiagnosed, and I remember, distinctly, my frustration with that...But I remember thinking to myself, 'I don't want to be a doctor, but I want to be someone in health care that helps solve the problems that other people can't.' ...and that's what attracted me: is that we take the time to listen, we take the time to be accurate, and we take the time to see the unusual and appreciate it.”

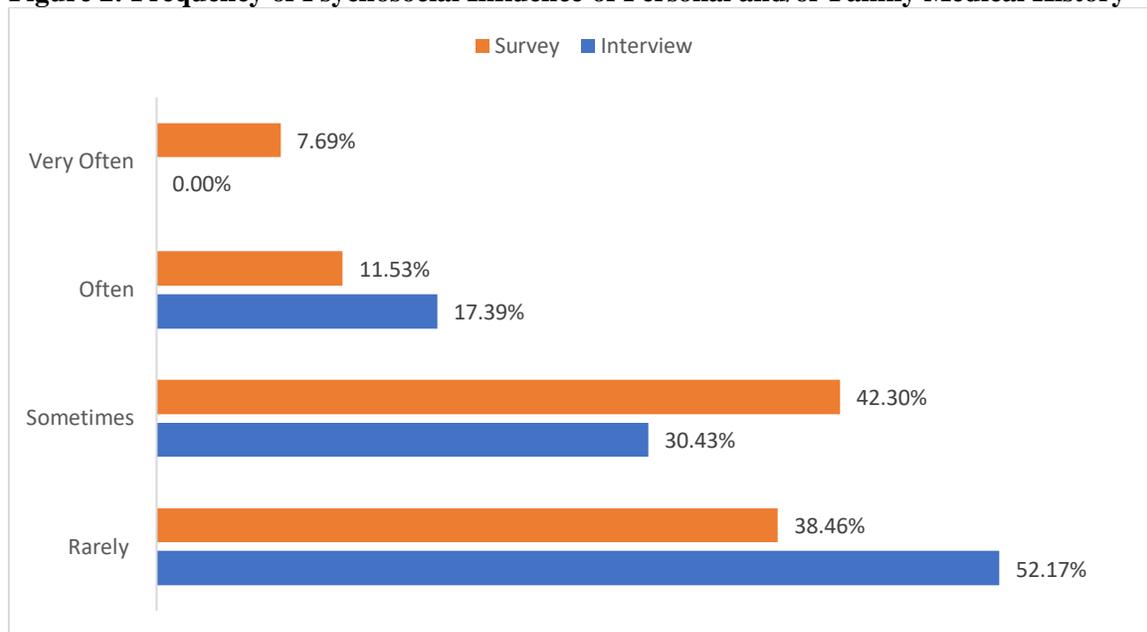
Apparent Thematic Differences

When comparing responses of Novice versus Experienced counselors, experienced genetic counselors talked about an increased passion for their field more often ($n=10$) than novice genetic counselors ($n=7$), (Table 3).

Psychosocial Influence

Survey participants were asked to indicate how frequently they think their personal and/or family medical history influenced their psychosocial practice within a session. For both survey ($n=40$) and interview respondents ($n=19$), the majority of genetic counselors indicated their personal and/or medical story rarely or only sometimes influenced their counseling, though there was not statistically significant difference ($p=0.385$), (Figure 2).

Figure 2: Frequency of Psychosocial Influence of Personal and/or Family Medical History



There are 10 overarching domains within Psychosocial Influence: subjective overview, countertransference, potential adverse effects on patient, compassion fatigue, denial, empathy, scope, self-disclosure, self-awareness, and rapport. Table 5 contains the domains, associated categories, and illustrative quotations.

Table 5: Psychosocial Influence

Psychosocial Influence			
Domain	Code	Frequency (n)	Response
Subjective Overview	Directly appraised their story with positive regard	13	<i>So I would say more positives than negatives.</i>
	Directly, negatively appraised the impact of their story	3	<i>And perhaps sometimes it's like wrongly directed, like perhaps sometimes I'm like, 'oh, I know, I must know how they feel because I went through something similar.' Like I could be totally off...</i>
Countertransference	Named or illustrated countertransference	20	<i>I just kept thinking, like, 'how could she be so calm about all of this? I don't think if I was in this situation, I would be.</i>
Potential Adverse Effects on Patient	Described some sort of repercussion for their patient	18	<i>...almost counterintuitively, I find that sometimes it can make me slightly less empathetic.</i>
	GC was tempted to judge or rank the severity of a patient's problem	7	<i>Overall...in the grand scheme of genetics and all of the conditions that we know people have, [medical condition] doesn't seem like the most devastating. It's not lethal. People have normal intelligence levels.</i>
Compassion Fatigue	Named or illustrated lasting emotional impact from interaction with a patient	15	<i>...if I can tell a family is struggling, sometimes I really take that home with me.</i>
	Demonstrated or narrated guilt/uncertainty	9	<i>...would just be very worried about saying, saying the wrong thing. Or, I don't know.</i>
Denial	Initially denied use of self-disclosure	14	<i>Like none really. I mean I feel like I self-disclosed to colleagues, and like done a presentation for students...</i>
	Denial of any psychosocial influence , or specifically countertransference	8	<i>You know, on a day-to-day level, it doesn't feel like it influences much of what I do, now...</i>
Empathy	Experienced increased empathy	17	<i>It gives me a greater understanding of what my patients are going through...</i>
	Attunement to patient experience	16	<i>...but I feel like I am especially attuned to that patient population because that's when I was diagnosed - like I was [age], when I was diagnosed.</i>
Scope	Increased scope of practice	21	<i>...So it's helped me ask better questions about the type of support</i>

			<i>they're getting from friends and family.</i>
	Felt more prepared or prompted to support/advocate for patient	14	<i>...to talk with patients to kind of just have that experience of wanting to be the person who can break bad news to someone or just kind of be there for them...</i>
	Unique perspective on family dynamic	13	<i>...now I can recognize the experience of the family members who were constantly remembering who their loved one used to be...</i>
	Fuller exploration/confrontation with patient	11	<i>I have been more probing in terms of someone's plans to disclose those results...</i>
Self-Disclosure	Gave at least one example of some sort of self-disclosure	19	<i>So that is usually only when I disclose - is if a patient directly asks me and, I feel like a direct response would be a benefit to them.</i>
Self-Awareness	Demonstrated or narrated self-awareness or moment of self-realization	14	<i>"So I take on stress more easily. I have to do a lot more like very active and proactive work on myself to keep myself in a space where I can emotionally be there for my patients.</i>
	Implemented or recognized/respected a boundary	14	<i>... because I now think I can recognize when it's [overidentification] happening, I am able to kind of pull myself back a little bit and kind of look at it, the situation, a little bit more from the professional side.</i>
Rapport	Narrated increased connection with patient	12	<i>Like, we have that shared experience of the condition...and so for many [...] patients...it does allow there to be a little bit more connection...</i>

Subjective Overview

During the interview, more than half of the counselors directly appraised the psychosocial influence of their story as positive ($n=13$), while only a few ($n=3$) directly, negatively appraised the influence of their story. Yet both positive and negative psychosocial implications were observed in the interview responses of participants.

Scope and Empathy

Almost all genetic counselors interviewed responded that they felt their medical history (personal and/or family) increased the scope of how they saw and cared for the patient ($n=21$), both practically and emotionally. Counselors more often talked about an increase in pragmatic scope ($n=18$) than an increase in emotional scope ($n=14$). Pragmatic scope included logistic or situational ways they could assist patients, such as better anticipatory guidance. Many genetic counselors felt more prompted to better support or advocate for their patients ($n=14$). Many also described a unique perspective or attentiveness to the patient's family members or family dynamic ($n=13$), while some genetic counselors ($n=11$) explained that they were more willing to explore or confront particular emotional moments with their patients because of their medical history.

“...but I can, I think, understand things on a deeper level than maybe a counselor who hasn't seen the day-to-day of a [medical condition]. Things that they don't think about, like potty training is a challenge...when they can't walk. So like, I know, I know little things like that because of my familial experience. And... so I have a little bit more insight on that.”

“And, you know, obviously the patients need counseling. But I feel like in those situations, I almost focus more energy on the family members and the caregivers to kind of make sure that, you know, they're understanding this because they're the ones who are, you know, pretty much having to deal with this and just making sure that they're getting support and that they feel like, you know, their needs are still important, even though they're being a caregiver for this person who's your patient.”

The majority of participants ($n=17$) also experienced and named an increase in empathy, specifically through an attunement to the patient's lived experience.

“I feel like I have this experience to draw on. And so I feel like it makes me especially empathetic to those patients.”

Self-Awareness

Many genetic counselors ($n=14$) demonstrated or narrated a practice of self-reflection, or moments self-realization or self-awareness, including acknowledgement of their own thresholds. Many ($n=14$) also discussed boundaries they recognized and respected in their sessions, or proactively implemented.

“Having a genetic condition myself definitely presents some bias when it comes to counseling families who are pregnant or had a past history of a child/fetus with a genetic condition. I am aware that it does negatively impact my psychosocial practice when the couple terminated a fetus due to a genetic condition, but I try to put myself in their shoes understanding not all genetic conditions are the same.”

Denial, Self-Disclosure, and Rapport

Most of the respondents ($n=14$) initially denied or downplayed their use of self-disclosure. Contradictory to their assertions, around half ($n=12$) narrated an increased connection with their patients, often associated with self-disclosure, and the majority of participants ($n=19$) gave at least one example of self-disclosure, whether indirect, prompted, support-motivated, or direct.

“[I self-disclose] very, very rarely. And it's tended to be more with either a patient where I saw them once, and it was kind of a very unique session in a way where I felt like... There was one, for example, where she was struggling with anxiety and struggling with what to do, and it just seems like she felt like those in her immediate circle were trying, but they didn't really understand how her brain worked. And so that was a session where I self-disclosed. I was like,

'Yeah, you know, I really struggle with anxiety, too. And I get where it goes this, this and this way.' And so that was a situation where I thought it would really help her if I self-disclosed."

Countertransference and Compassion Fatigue

Some of the respondents ($n=8$) denied any type of psychosocial influence, such as countertransference. However, most ($n=20$) named or illustrated countertransference during their interviews.

"Like I had a patient tell me about her nephew who had the same diagnosis as me, initially, who didn't respond to treatment. Who went down mostly the same treatment path and then ultimately died. But he went through the [medical treatment] that I declined. And I remember that moment thinking - and I had not disclosed, really to her, any of this - but I was thinking: 'Gosh, I might have dodged a bullet there, by being kind of a rebel.' Because it was a common story."

"And I kind of brought up the fact that, like, 'Perhaps it would be hard for you to test positive and still be able to focus on your mom and sister, knowing that that might one day be you.' And he was like 'No, that's not it.' So that was - I definitely noticed that I was kind of like putting myself in their shoes a little bit presumptuously."

More than half of the participants ($n=15$) described lasting emotional impact from an interaction with a patient, because of their history, while a smaller number of counselors ($n=9$) demonstrated or narrated guilt or uncertainty in the way they chose to engage a patient, or in the aftermath of a session.

"When I go home and I try not to think too much about the patients that I'm seeing - but I do feel like that girl in particular, I thought a little bit more about when I went home than I do about most patients. It was like a little bit harder for me to dissociate work from my personal life, just because that was something that almost kind of fit in with my personal story..."

Potential Adverse Effects on Patients

Most genetic counselors narrated or described some sort of potential adverse effect on their patient ($n=18$), which could include projection, disengagement, or more directive counseling. Specifically, some counselors ($n=7$) felt themselves judging a patient's experience or felt tempted to rank the patient's diagnostic experience as it compared to their own.

“But maybe a slightly less obvious answer would be that sometimes, almost counterintuitively, I find that sometimes it can make me slightly less empathetic, in that because I have gone through the diagnostic odyssey, sometimes I find myself, you know, sometimes frustrated with patients who are panicking, in abject existential panic over what I would consider 'nothing.’”

Apparent Thematic Differences

Experienced genetic counselors ($n=9$) were more likely to appraise the positive impact of their story on their practice, compared to novice genetic counselors ($n=4$). Experienced genetic counselors were also more likely to describe the presence of psychosocial implications such as increased empathy, increased emotional scope, fuller exploration of content with patients, and support or advocacy for their patients. Novice genetic counselors were more likely to feel tempted to judge or compare their patient's experienced to their own (Table 3).

DISCUSSION

To our knowledge, this is the first study specifically exploring how genetic counselors' personal and/or family medical history affects their choice of specialty as well as their psychosocial practice. What appeared most crucial was the way in which a genetic counselor understood, appreciated, and cared for the import of their own medical story.

There were differing depths of perceived emotional intensity among participants regarding their personal medical stories, as well as differing levels of participants' relationships with the affected individual(s). This spectrum could be due to a difference of adjustment and identity: individuals who experienced a diagnosis at a young age, or grew up with an affected family member, may have more fully accepted and integrated their experience in such a way that it became part of the fabric of their lives and is no longer perceived as challenging (34, 35). Other counselors may still be adjusting to the implications of a diagnosis in their adult life. The spectrum of perceived severity may also be due to the level of self-reflection and inner work the counselor had invested in, or it may be simply a byproduct of the unexplainable tragedy that impartially but unevenly marks individuals' lives. Delving further into the temporal relationship of the diagnosis to tease apart the relationship may be a fruitful area for further research.

Since students are in their third decade of life by the time they enter graduate school, most participants encountered their personal or family medical diagnosis prior to their graduate school experience. When family histories extended beyond one individual, the most prevalent narrated family history tended to be centered on key individuals who participants had frequent direct interaction with such as a childhood neighbor or live-in grandparent, while the rest of the extended family history was communicated about more collectively.

Within the narrative of a genetic counselor's medical journey, patterns of seemingly disparate psychosocial concepts seemed to group together, for example, *unresolved dynamic* coded with *countertransference*, *judgment*, *temptation to rank severity* and *projection*. There were also paradoxical clusters of codes such as *severe loss/trauma* being coded with *guilt or uncertainty*, but also with *deeper appreciation for human complexity*, and *honesty in loss*. This may be because pain can produce psychological insight to the human experience along with residual burden (36). Largely, however, specific patterns characterizing types of medical histories were not found in this study. For example, participants with *recent diagnoses* were not uniformly observed with other, specific psychosocial manifestations, although this could be confounded by the participant's inability to understand what they

are still navigating. The small sample size precludes conclusions about the impact of type of medical history.

Overall, it appeared that medical histories had a positive or neutral impact on specialty choice. Most genetic counselors were either drawn to a specialty they associated with their medical history or identified other factors as weighing more heavily in their specialty decision. This observation included many of the counselors who narrated severe loss or trauma, yet still desired to pursue a specialty that overlapped with their story. Genetic counselors who said their story had no influence on their specialty choice pointed to intellectual intrigue, board preparation, formative exposure, circumstantial framework, situational constraints, or personal preference instead. Yet, even when circumstance took initial priority in specialty decision, genetic counselors communicated remaining attracted to story-similar specialties, hindered only by job availability or the absence of a correlating specialty position. Interestingly, four genetic counselors belatedly recognized their attraction to a position as connected to their medical history.

Very few participants actively avoided a specialty because of their medical history, and only a few instances of specialty change in reaction to a negative experience were observed. It is unclear whether this is a general trend that carries across counselors or is due to selection bias for this study against participation by those who actively avoid reminders of their stories. Some specialty changes were observed throughout the interviews, but these changes were more likely a product of either the natural career evolution, or emerging opportunities that allowed the genetic counselor to finally take position within a specialty connected to their medical history. Of note, one genetic counselor explicitly demonstrated both attraction and repulsion to specialties, based on the multi-faceted experience of her medical history.

When considering the psychosocial influence on participants, there was a significant disconnect between the interviewees responses to the online survey, and the observed, descriptive interview responses. The majority of the survey and interview samples reported that psychosocial implications from their story rarely or infrequently occurred, while interview observations offered contradicting

evidence, with all interviewees discussing some evidence of impact over the course of their interview. Furthermore, many interviewees denied any type of perceived psychosocial implication from their story, including countertransference. Discrepancy between stated and observed impact could be due to a varied understanding of the comprehensiveness of psychosocial manifestations: it could be a result of nuances that a survey question cannot capture compared to a live interview, or it could suggest a lack of self-awareness. Do genetic counselors understand that their history, medical or not, gives them a distinct lens through which they engage and receive others? (10) Regardless of its source, this disparity is notable.

Countertransference, in particular, was not a concept genetic counselors seemed comfortable acknowledging within their practice. Gelso and Hayes explain that experience of countertransference is universal and unavoidable, and its utility or detriment lies in the psychotherapists ability to identify and manage it (24). Why should genetic counselors be different? A few participants described moments of this phenomenon, yet for most, its occurrence was either denied or unrecognized despite the majority of counselors narrating or demonstrating countertransference in their interview responses. Genetic counselors possibly do not recognize that countertransference can be two-fold; there is an internal experience of it, which may or may not be followed by a behavioral ramification (37). Thus, admitting to countertransference does not by itself indicate there were ramifications for the patient. Perhaps this distinction would allow genetic counselors to admit to countertransference, if they could separate it from always causing harm to their patients. On the contrary, if countertransference is altogether dismissed, then the opportunity to respond to it in such a way that protects the patient might be missed.

Self-disclosure proved to be another area tangled with contradicting assertions and acceptance. Examples of self-disclosure were frequently given, though the use of self-disclosure was also initially denied or downplayed as infrequent. Even when interviewees discussed the purpose of their disclosure to be support-motivated or as a way of strengthening their credibility, uncertainty marked their discernment of its appropriateness. One acknowledged origin of this conflict was the participants' training curriculum, in which some counselors recalled being encouraged to 'never' self-disclose (10). Recollection of this black and white rule belies the nuance found in Veach's review of a clinician's self-

involvement within a session (38). This review offers a call to consciousness for each practitioner: inviting a deliberately thoughtful choice as to why, how and when to share one's story with a client, rather than operating under the framework of an absolute guideline (38).

Although burnout is not a phenomenon that could be thoroughly assessed in this study, other research describes how interpersonal experiences of the genetic counselor can lead to more permanent detriment such as compassion fatigue or potential burnout. Past studies have also identified many genetic counseling cohorts at high to moderate risk for compassion fatigue due to long-lasting emotional effects in the patient-counselor relationship (39, 40). In 2016, Johnstone and colleagues found that 40% of 353 surveyed genetic counselors considered leaving or did leave their jobs because of burnout. If the genetic counseling population is at risk for burnout, and interpersonal dynamics with patients have been seen to contribute to this path, it is important to consider how the added layer of medical histories that parallel patient histories could affect potential burnout, through occurrences such as countertransference and compassion fatigue.

Despite this seeming lack of acceptance of countertransference and psychosocial permeation, the large majority of the interview sample stated that his or her story empowers them and has a positive bearing on their practice. Increased psychosocial scope and empathy were the most commonly accredited ways in which a counselor's medical history assisted their counseling. Genetic counselors described confidence and efficacy in their communication with patients, rooted in their first-hand experience of a condition or diagnosis. Whether describing a procedure, treatment, support system, or hospital advice, the counselor's ability to care for a patient beyond the clinic visit seemed to be enhanced by his or her own experience. Empathy appeared throughout the interview process, often fitting in Barrett-Lennard's three phases of empathy: reception from the listener, responsive communication from the listener, and received empathy from the individual who is sharing (41). Empathy was one of the more frequently reported and observed concepts within interviews, suggesting a more authentic and natural ability of counselors with medical histories to emotionally align with their patients. Additionally, a counselor's demonstrated or claimed emotional intuition seemingly had less to do with his or her specific medical

history, and more association with the universal experiences of loss, trauma, grief and the formative exposure of simply being a patient (42).

Cumulatively, participants' interactions with patients reflected Nouwen's idea of a 'wounded healer,' where both the practitioner and patient mutually experience a sort of healing or redemption from their relationship (22). In this overarching framework, counselors narrated an ability to care for their patients out of their own experience with tragedy, allowing patients to experience a fuller understanding and sensitivity from their provider, and allowing the counselor to experience increased satisfaction in their work.

In effort to assess how years of experience played a role, we compared code frequencies between novice and experienced genetic counselors. There was little difference between the two groups in terms of medical history background and specialty influence. When looking at the effects of psychosocial impact, the experienced genetic counselor cohort exhibited higher frequencies of several concepts, both positive and negative. This may be due to chronology, as experienced genetic counselors have had more time to develop a robust language and understanding with which to describe what they experience in a session. At the same time, while it might be anticipated that genetic counselors who have practiced longer may greater sense of self-awareness, our observations generally did not support this assumption. Experienced counselors, on the whole, did not more readily accept countertransference, demonstrate greater liberty with the use of self-disclosure, or even acknowledge the comprehensiveness of psychosocial implications their medical experience afforded. Perhaps this is because a genetic counselor's journey is dynamic, and that the impact of medical history produces varying phases of residual trauma and growth throughout the course of a medical professional's life.

Study Limitations

While the sample was reflective of the current NSGC membership according to the Professional Status Survey (PSS), the small sample size and homogeneity remain limitations of the current study. Another significant limitation was in our inability to account for ascertainment bias within our sample.

For instance, our sample contained more genetic counselors who were attracted to specialties because of their medical history than were repelled. However, it is possible that counselors who wanted to avoid certain specialties because of their medical history chose not to participate due to the negative feelings brought on by discussing their history. Similarly, it was not possible to determine whether some participants subconsciously used the study interview to process through their experiences, while others who had previously worked through their story declined to participate.

When participants were asked about their medical history's impact on specialty choice, it is possible they assigned a positive association with 'impact' and chose to describe attraction over avoidance. Confusion between attraction to the general field as opposed to a particular specialty may have skewed responses. Medical family histories also proved difficult to categorize. Many participants had multiple family members affected with a variety of conditions, and the scope of this study could not account for the influence of these many layers. Finally, observations were dependent on participants' ability to truthfully reflect and self-report their story lending to implicit bias and subjective interpretation of psychosocial concepts. While six transcripts were coded for consistency between the Principal Investigator (PI) and last author, this type of inductive analysis is similarly dependent on the investigators' lens through which they interpreted the occurrences within each interview and could equally be affected by subjectivity and bias.

Practice Implications

This study provides insight into the ways a genetic counselor perceives the effects of his or her personal and family medical experiences on their practice. Namely, these histories promoted increased awareness of the patient experience and enhanced empathy. However, many participants did not name or recognize the amount of countertransference and self-disclosure apparent in their patient care, or felt shame in having done so. Both genetic counseling training programs and post-degree career development programs could be used to shape a genetic counselor's practice of self-reflection to more specifically address understanding of and ambivalence toward self-disclosure and countertransference. While in

training, students could be encouraged to name their own encounters with medicine from the patient side, and more pointedly discuss anticipated implications of such encounters. Training and/or peer supervision could be more focused on naming and discussing observed countertransference and empathy. Similarly, it would benefit counselors who have or acquire significant medical histories, and secondarily, their patients, to commit to a more in-depth form of self-reflection. Such inner work could include regular journaling, peer discussion/supervision groups, and psychotherapy. Additionally, it may be beneficial to emphasize that psychosocial concepts such as self-disclosure and countertransference should not be discussed as dichotomous, never-or-always, but rather, that the ultimate goal of the counselor is to foster nuanced discernment in their patient care.

Research Recommendations

Additional studies with a larger sample size and more diverse representation of genetic counselors could be used to more precisely analyze the unique and combined impacts of medical histories and years of experience on genetic counselor specialty choice. Quantitative studies could also be used to more directly relate medical history characteristics with psychosocial practice and outcome, such as recency of diagnosis with experience of over-identification.

Conclusion

Medical histories, like other formative facets of life, can motivate and empower genetic counselors to become more empathic and able to appreciate the impact of illness, even while fulfilling their own sense of purpose born out of pain. These personal and family medical stories can integrate with mature skill development and become a great asset to counselors' effectiveness with patients, as they embody the vocation of a wounded healer. However, genetic counselors' stories are also fraught with opportunities to devolve, limit growth, and negatively impact patients they have been entrusted with due to unrecognized countertransference. This reality requires honesty, inner work and reflection to navigate

and truthfully understand how the story they are living creates the lens through which they understand their practice.

APPENDIX

Supplemental Table I: Codes and Code Categories

Medical Story Codes		
Diagnostic Experience	Emotional Formation	Counseling Experience
Prior to Graduate School	Premature Caregiver Role	Conflict with Training
Recent Diagnosis	Acquaintance with Trauma or Loss	Survivor's Guilt
Multiple Family Members Affected	Isolated	Resonant Experience
Abrupt/Major Life Transition	Adjusting/Well-Adjusted	Personal Preference or Intellectual Attraction
Misdiagnosis/Misinformation	Narrated Coping Strategy:	Discomfort/Lack of Familiarity
Proximity To Affected Individual/Relational Closeness	Avoidance	
Received Genetic Counseling	Intellectualizing	
	Normalizing	
	Mentor/Ally	
	Unresolved Story	

Specialty Influence Codes			
Attraction	Aversion	Alternative Influence	Field-Related Movement
Meaning-Making/Fulfilling	Lack of Control	Circumstance/Opportunity	Changed Specialty (Toward or Away)
Desire to Redeem Story	Self-Protection/Specifically-Informed Fear	Evolution of Field/Specialty Didn't Exist	No Specialty Change
Sense of Control	Acknowledged Emotional Threshold	Board-Motivated	Described Motivation Toward General Field
Passive Recognition of Attraction		Formative Exposure	
Equipped/Depth of Knowledge/Familiarity		Personal Preference/Intellectual Attraction	
Increased Passion		Discomfort/Lack of Familiarity	

Psychosocial Influence Codes (Positive)				
Empathy	Scope	Rapport	Self-Disclosure	Self-Awareness
Attunement to Patient Experience Appreciation of Human Complexity	Pragmatic Scope: Equipped/Familiarity Realistic Anticipatory Guidance Grasp Patient Context Emotional Scope: Honesty about Loss Fuller Exploration of Subject Reassurance Validation Intuition Better Perspective of Family Heightened Discernment Support/Advocate	Credibility/Trust-Building Increased Connection	Direct Indirect Prompted Unrelated Selective Support-Motivated Timing	Self-Awareness/Reflection/Realization Acknowledged Emotional Threshold Boundary Corrected Projection Recognized Bias Open-Minded/Accepting Perspective Shift

Psychosocial Influence Codes (Negative)				
Countertransference	Compassion Fatigue	Denial	Potential Adverse Effects on Patient	Additional Observations
Over-identification Triggering Projection Over-Emphasis of Subject	Compassion Fatigue Lacking Boundary Intentional Effort to Stay Connected Lasting Emotional Impact Guilt/Uncertainty	Denial of Self-Disclosure Denial of Countertransference Denial of Psychosocial Influence	Judgment Projection Loss of Trust Disengagement Directive/Advice Giving Over-Emphasis of Subject Transference	Life Cycle/Role Implication

Supplemental Table II: Types of Medical Histories

Types of Family History	
Survey	Interview
Autoimmune Conditions	Autoimmune Conditions
Bleeding & Clotting Disorders	Bleeding & Clotting Disorders
Cancer / Hereditary Cancer Predisposition	Cancer / Hereditary Cancer Predisposition
Cardiac Conditions	Cardiac Conditions
Chromosomal Anomalies	Chromosomal Anomalies
Chronic Pain	Chronic Pain
Chronic GI Conditions	Chronic GI Conditions
Connective Tissue Disorders	
Hemoglobinopathies	Hemoglobinopathies
Metabolic Conditions	Metabolic Conditions
Multifactorial	Multifactorial
Musculoskeletal	Musculoskeletal
Neurological/Neuromuscular	Neurological/Neuromuscular
Other, Inherited Genetic Predispositions	Other, Inherited Genetic Predispositions
Psychiatric	Psychiatric
Rheumatological	
Single Gene Disorders	

Types of Personal History	
Survey	Interview
Autoimmune Conditions	Autoimmune Conditions
Bleeding & Clotting Disorders	Bleeding & Clotting Disorders
Cancer / Hereditary Cancer Predisposition	Cancer / Hereditary Cancer Predisposition
Cardiac Conditions	
Chronic GI Conditions	
Connective T3issue Disorders	
Metabolic Conditions	Metabolic Conditions
Multifactorial	
Musculoskeletal	
Neurological / Neuropathies	
Neuromuscular	
Other Genetic Syndromes	
Other, Inherited Genetic Predispositions	Other, Inherited Genetic Predispositions
Psychiatric	Psychiatric
Rheumatological	
Single Gene Disorders	Single Gene Disorders

Supplemental Document I: Survey Questions

1. Do you have either a personal **or** family medical history of a genetic condition, major illness or genetic predisposition?
bulleted options: Yes or No
If no → skip to end of survey
If yes → go to Q2
2. Are you a certified genetic counselor or board eligible genetic counselor?
bulleted options: Yes or No
If no → skip to end of survey
If yes → go to Q3
3. What is your current age?
empty text box
4. What is your gender?
drop-down options:
 - female
 - male
 - non-binary
 - transgender male
 - transgender female
 - other
 - prefer not to disclose
5. With which ethnicity do you most identify?
drop-down options:
 - American Indian or Alaskan Native
 - Asian
 - Asian Indian
 - Bi-racial (Please specify)
 - Black or African American
 - Caucasian or White
 - Hispanic/Chicano/Latina(o)
 - Native Hawaiian or other Pacific Islander
 - Other (Please Specify)
 - Prefer Not to Answer
6. How many years have you been working as a genetic counselor? (If less than 1 year, please put “1”)
empty text box: _____ year(s)

7. Which of the following best describes your primary work setting?

drop-down options:

- Bioinformatics Company
- Diagnostic Laboratory (Commercial, Non-academic)
- Diagnostic Laboratory (Non-commercial, Academic)
- Federal/State/County Office
- Government Organization or Agency
- Health Advocacy Organization
- Health Maintenance Organization
- Internet/Website Company
- Marketing/Advertising Company
- Not-For-Profit Organization
- Outreach/Satellite/Field Clinic
- Pharmaceutical Company
- Private Practice/Self-employed
- Professional Organization
- Public Hospital / Medical Facility
- Research Development/Biotechnology Company
- Telegenetics
- University Medical Center
- University/Non-medical Center
- Other

8. What was your **first primary** area of practice/specialty after graduation? (Please check one)

drop-down options:

- Administration
- Cancer
- Cardiology
- Cystic Fibrosis
- Education, Public or Professional
- General Genetics
- Genomic Medicine
- Genomic Profiling/Personal Genomics
- Hematology
- Infertility, ART/IVF
- Laboratory
- Metabolic Diseases (including Lysosomal Storage)
- Neurogenetics
- Newborn Screening
- Pediatrics
- PGD
- Pharmacogenetics
- Post Mortem
- Preconception/Reproductive Screening
- Prenatal
- Psychiatric
- Public Health
- Research
- Specialty Disease
- Other

9. How many years did you work in your first, **primary** specialty? (If less than 1 year, please put “1”)
empty textbox: _____ year(s)

10. What is your current, primary specialty area?

drop-down options:

- Administration
- Cancer
- Cardiology
- Cystic Fibrosis
- Education, Public or Professional
- General Genetics
- Genomic Medicine
- Genomic Profiling/Personal Genomics
- Hematology
- Infertility, ART/IVF
- Laboratory
- Metabolic Diseases (including Lysosomal Storage)
- Neurogenetics
- Newborn Screening
- Pediatrics
- PGD
- Pharmacogenetics
- Post Mortem
- Preconception/Reproductive Screening
- Prenatal
- Psychiatric
- Public Health
- Research
- Specialty Disease
- Other:

11. How many years have you worked in your current, primary specialty area? (If less than 1 year, please put “1”)

empty text box: _____ year(s)

12. What is your current, **secondary** specialty area?
drop-down options: If “None” → skip to Q14

- None
- Administration
- Cancer
- Cardiology
- Cystic Fibrosis
- Education, Public or Professional
- General Genetics
- Genomic Medicine
- Genomic Profiling/Personal Genomics
- Hematology
- Infertility, ART/IVF
- Laboratory
- Metabolic Diseases (including Lysosomal Storage)
- Neurogenetics
- Newborn Screening
- Pediatrics
- PGD
- Pharmacogenetics
- Post Mortem
- Preconception/Reproductive Screening
- Prenatal
- Psychiatric
- Public Health
- Research
- Specialty Disease
- Other

13. How many years have you worked in your **current, secondary** specialty area? (If less than 1 year, please put “1”)

empty text box: _____ year(s)

14. Do **you, the genetic counselor**, have a personal history of a genetic/medical condition, major illness, or predisposition to a genetic condition?

bulleted options: Yes or No

If no → skip to Q21

If yes → go to Q15

15. Please describe the type of genetic/medical condition, major illness or genetic predisposition:

open-ended/blank text box

16. At what point in your journey to genetic counseling were you first aware you had this medical/genetic condition, illness or genetic predisposition?

drop-down options:

- Prior to your graduate school training program in genetic counseling
- During your graduate school training program
- After your graduate school training program in genetic counseling
- Unsure

17. Is the condition/illness physically visible on a typical work-day?

drop-down options:

- not at all visible
- barely visible
- somewhat visible
- visible
- very visible

18. How much did your personal genetic/medical condition, major illness or genetic predisposition influence your choice of your **first** practice specialty after graduate school?

bulleted options:

- 0 = did not influence
- 1 = little influence
- 2 = some influence
- 3 = a fair amount of influence
- 4 = a great deal of influence

19. Do you have more than one area of specialty focus?

bulleted options: Yes or No

If no → skip to Q21

If yes → go to Q20

20. How much did your personal genetic/medical condition, major illness or genetic predisposition influence affect your choice of your **current** practice specialty?

bulleted options:

- 0 = did not influence
- 1 = little influence
- 2 = some influence
- 3 = a fair amount of influence
- 4 = a great deal of influence

21. Does a **first, second or third degree relative** have a personal history of genetic/medical condition, major illness, or predisposition to a genetic condition??

bulleted options: Yes or No

If no → skip to Q28

If yes → go to Q22

22. Who in your family has/had the genetic/medical condition, major illness or genetic predisposition?
(Please check all that apply)

check-box options:

- mother or stepmother
- father or stepfather
- sibling or halfsibling
- your child(ren)
- aunt or uncle
- niece or nephew
- cousin

- grandparent

23. Please describe your family member(s) type of genetic/medical condition, major illness, or genetic predisposition: (If multiple family members, please list the different, relevant medical conditions.)

open-ended/blank text box

24. At what point in your journey to genetic counseling was a family member first diagnosed, or at what point was the first genetic/medical condition, illness or predisposition discovered?

drop-down options:

- Prior to your graduate school training program in genetic counseling?
- During your graduate school training program in genetic counseling?
- After your graduate school training program in genetic counseling?
- Unsure

25. How much did this family member(s)' medical history influence your choice of your **first** genetic counseling specialty after graduate school?

bulleted options

- 0 = did not influence
- 1 = little influence
- 2 = some influence
- 3 = a fair amount of influence
- 4 = a great deal of influence

26. How much did this family member(s)' medical history influence your choice of your **current** genetic counseling specialty?

bulleted options

- 0 = did not influence
- 1 = little influence
- 2 = some influence
- 3 = a fair amount of influence
- 4 = a great deal of influence

27. Do you currently provide genetic counseling services directly to patients?

bulleted options: Yes or No

If no → skip to end of survey

If yes → go to Q29

28. Please briefly describe one way, if at all, your personal and/or family medical history influenced your choice of practice specialty:

open-ended/blank text box

29. Please briefly describe one way, if at all, your personal and/or family medical history has influenced your psychosocial practice:

open-ended/blank text box

30. How often does your personal medical condition influence your psychosocial practice?

bulleted options:

- 0 = not at all

- 1 =rarely
- 2 = sometimes
- 3 = often
- 4 = very often

31. Would you be willing to participate in a telephone interview for approximately 30 minutes to discuss how your personal or family history has impacted your choice of specialty and genetic counseling practice?

If no → skip to end of survey

If yes → go to Q33

32. Please provide the following contact information for a possible telephone interview:

Name:

Phone:

Email:

Supplemental Document II: Interview Script

1. Your answers to the short survey indicated that:
 - a. You/your family member had _____ (name of diagnosis)
 - b. the genetic/medical condition or illness is _____ (visibility)
 - c. the genetic/medical condition, illness or genetic predisposition was discovered _____
(timing of diagnosis)
 - d. the genetic/medical condition, illness or genetic predisposition had _____ (influence
specialty choice)

2. What was the specific genetic/medical condition, illness or genetic predisposition?

3. Tell me how you first learned about the genetic/medical condition, illness or genetic predisposition:

4. At what point in your training or career did that story impact your choice of specialty?
[Undergraduate? Training program? In the middle of your career?]

5. How did it affect your choice?
[Why did you, or did you not choose _____ because of your experience?]
[If you transitioned specialties – how did the genetic/medical condition, major illness or predisposition impact your decision to change specialties?]

6. Did you ever change specialties because of your genetic/medical condition, illness or genetic predisposition?

7. How has the genetic/medical condition, illness or predisposition affected the way you counsel (psychosocially)?
[Describe your story's influence on your practice methods.]
8. In what ways, if any, has this genetic/medical condition, illness or genetic predisposition positively affected your professional practice?
9. In what ways, if any, has this genetic/medical condition, illness or genetic predisposition negatively affected your professional practice?
10. Do you ever tell a patient part of your story? Under what circumstances? Please give an example of a time when you told a patient a part of your story?
[Prompts: What you said? Why? What effect did it have?]
11. When you hear patient stories that are similar to your own what effects does it have on you?

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VITA

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