Portrait of the Master Genetic Counselor:

A Qualitative Investigation of Expertise in Genetic Counseling

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

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

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August 2012

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Acknowledgements

"Some people come in our lives and quickly go. Some stay for a while and leave footprints on our hearts, and we are never, ever the same."
~Author Unknown

My heart carries the footprints of so many, and I am so grateful.

Thank you to the master genetic counselors who opened their hearts and practices for the interviews. I hope I have captured at least some of the essence that you graciously shared with me through your willingness, openness, stories and wisdom. I thoroughly enjoyed our conversations.

Thank you to CSPP graduate students Shawn Mason and Carolyn Quisenberry for your time, energy, insights and perspectives in analyzing the interviews. Your collaboration added subtleties and richness this work.

Many, many thanks to my adviser Pat McCarthy Veach and to Michael Goh. Both of you embody the depth, strength and character that is CSPP. From your caring, genuineness, authenticity, and positive regard I learned the "heart and soul" of the work. Thank you for your insight, support, diplomacy, anticipatory guidance, and for sticking with me. I am honored to have learned from the best of the best.

Thank you to CSPP faculty John Romano, my very first graduate school professor so long ago, who confirmed in my mind that I had made the right choice, and to Tom Skovholt whose work provided the basis for this study (as well as a developmental model that [*whew!*] normalized my novice anxiety during my Master's program). Thanks to my committee members who guided this project and helped in seeing it through. To Bonnie LeRoy for your indispensible input, connections, and just

the right touch of irreverence. And to Matt Hanson who was there at my graduate school beginning and now, full-circle, at its conclusion.

Thank you Canan Karatekin for helping me learn to "think like a scientist," for the child development anchor of my lifespan perspective, for assessment experiences, and especially for assistantship support that made the rest possible. I could never believe I was getting paid for what I was learning in your lab. Any references to operational definitions are for you. (And present page-count aside, my reports are much more succinct these days!)

In addition to academic learning, significant therapist development occurs in the counseling room. Thank you to my clients for the honor and trust in letting me walk with you on your journey. Thank you Pat, Jerry Shih, and Trisha Stark for the gift of phenomenal supervision along my own professional journey. Your guiding wisdom in supervision is an integral part of how I practice. Thank you for allowing me to stretch, make mistakes, and see what I could not see. My supervision experience has been awesome and profound. I hope I can "play it forward".

I am deeply honored for the wisdom and counsel of master therapist Jan Schaub. Your footprints are forever integrated into my heart and practice. When the student was ready the teacher appeared. I am so appreciative on so many levels.

I am filled with gratitude for my dear friend and colleague Tonie VanStelten. What would I do without your understanding of the psychological 1% and its relationship to the scenery? Spring is here. Here's to adventure! Thank you, my friend.

Likewise, thanks to Bonnie Houg, my long-time friend and colleague, who once in supervision advised, "When in doubt, go back to the relationship." It is so true in

counseling and in life. I would not be at this point without your sharing and understanding, our in-depth life processing and, of course, iced tea.

Thank you Nancy Doyle and Beth Scheunemann for your on-going friendship and unwavering support. I am blessed to have such friends.

Finally, my deepest love, thanks and gratitude to my family, who walked with me *every* step of this journey, never gave up, and supported me in so many, many ways. Thank you, Mom and Kenny, for unconditional love. Thank you Cali, my sister and best friend, and my brother Derf, who taught me what is important in life.

And most importantly, to my children, Matthew and Mallory. Thank you from the bottom of my heart for *everything*. I could not have done it without you. I love and cherish you to the depths of my soul.

Dedication

Beyond words, this book is dedicated with so much love to

Mom & Kenny

My sister Cali

And most of all, to my constant inspirations and joy

My dear children, Matthew and Mallory

"You are the best of all the rest."

Abstract

This study begins to describe personal and professional characteristics of master genetic counselors—those considered to be experts or among the best-of-the best clinicians in genetic counseling. The focus of the investigation was the *person* of the master genetic counselor. Fifteen, peer-nominated genetic counselors participated in in-depth, semi-structured telephone interviews exploring their personal qualities, inspirations, motivations, strengths, struggles, and professional development. Analysis using a modified version of Consensual Qualitative Research (Hill, 2012) resulted in four broad themes: 1) Personal Characteristics of Master Genetic Counselors, 2) Relationships with Patients, 3) What Constitutes Success, and 4) Views of the Profession. Findings indicate master genetic counselors: a) have insatiable curiosity, love learning and are life-long learners; b) are reflective, self-aware, confident and recognize their limitations; c) are authentic and genuine, and consider their personality to be their counseling style; c) form collaborative and interactive relationships with patients based on trust; d) have nuanced attunement to the complexity and multiple levels of the counseling *process*; e) struggle when they cannot connect with patients; f) have deep empathy, are inspired by patients, and derive personal meaning from their work; g) are affected emotionally by their work, but effectively manage the emotional impact; h) view success as patient-centered and based in the patient/genetic counselor relationship; i) view their professional development as ongoing; and j) hold various perspectives on psychosocial aspects of genetic counseling, on the art vs. science nature of the field, and development of the profession. Major findings are discussed in conjunction with theory and previous research. The findings provide strong support for the Reciprocal-Engagement Model of

genetic counseling practice (McCarthy Veach, et al., 2007). Study strengths and limitations, implication for training and practice, and research recommendation are discussed.

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Chapter 1

Significance of the Problem

Genetic counseling is of multiple worlds. One realm encompasses microbiology, "the facts and figures of genetics and medicine" (Abrams & Kessler, 2002, p.5); others encompass the social realm of family, and the psychological realms of personal meaning, emotions, morals and, often, decision-making. Genetic counseling is a profession that is at once biological and medical, social and psychological. And at the ever-fluctuating intersection is the genetic counselor. Genetic counselors translate medical facts and risk statistics into language patients can understand. They are instructors of human inheritance, of microbiological diagnoses, and of the inner workings of the health care and genetic universes.

Yet genetic counselors' role extends far beyond that that of information provider. "Indeed, genetic counselors are active and compassionate participants in patient' efforts to understand their genetic risks, endure their emotional struggles, and make life-altering decisions," note LeRoy, McCarthy Veach and Bartels (2010, p.1).

As such, genetic counselors assist patients who face personal situations that can be traumatic and stress-inducing (Weil, 2000). They counsel and support patients and their families in making decisions, coping, and adjusting psychologically (Weil, Ormond, Peters, Bisecker, & LeRoy, 2006) to shame, guilt and grief (Kessler, 1984), anxiety, uncertainty, depression, feelings of helplessness, as well as the potential burden of loss (Davey, Rostant, Harrop, Goldblatt, & O'Leary, 2005).

This "complex, dynamic and multi-faceted endeavor" (Biesecker & Peters, 2001, p. 1992) requires understanding human behavior, reactions and dynamics as well as the

individual life circumstances of the family involved (Lippman-Hand & Frazer, 1979). A pregnant woman may learn that her fetus carries a genetic anomaly likely to result in severe mental retardation or early death. A young woman may face the option of greatly increased risk of the breast cancer that killed her mother, or radical surgery to prevent an occurrence that might not happen. A young man may decide on testing to learn if he carries the gene for Huntington's disease, preferring certainty and reality over uncertainty and anxiety. Further, as presymptomatic genetic testing becomes more routine and as understanding of the genetic influences on disease increases, genetic counselors' roles are expected to expand into prevention and treatment of common, chronic conditions (Jay, Afifi, & Samter, 2000; Wang, Gonzalez & Merajver, 2004). Consequently, more patients will come in contact with genetic counselors (Gray, McCarthy Veach, Jones, Goreczny & Hoss, 2000; National Society of Genetic Counselor' Definition Task Force, 2006.)

The most current definition of genetic counseling describes it "as a process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions of disease"… including "interpretation of family and medical history to assess the chance of disease occurrence or recurrence, education about inheritance, testing, management, prevention, resources, and research, [and] counseling to promote informed choices and adaptations" (National Society of Genetic Counselors' Definition Task Force, 2006, p. 77). The definition also includes performing psychosocial assessment to identify emotional, social, educational and cultural issues, evaluating the client or family responses to the condition or risk of occurrence, providing client-centered counseling and anticipatory guidance, and promoting informed decision-making (Biesecker & Peters, 2001).

Yet to date, little published research has documented how genetic counselors *best* perform their myriad of roles. Even fewer published studies explore the *personal characteristics* or *professional development* that might underlie what it takes *to excel at* these roles. The American Board of Genetic Counseling's practice-based competencies require genetic counselors to demonstrate commitment to professional growth and life-long learning (American Board of Genetic Counseling, 2007). Yet there are scarce data about the professional development of genetic counselors (Zahm, 2009), and no comprehensive data about what might be considered optimal development. Optimal development likely is a complex process influenced by numerous factors. Understanding the factors underlying optimal professional development takes on increased saliency in light of risks for burn out and compassion fatigue (Benoit, McCarthy Veach, & LeRoy, 2007; Udipi, McCarthy Veach, Kao & LeRoy, 2008) and attrition in the field (Parrot & Del Vecchio, 2006). And, equally important, little is known, about protective factors that keep 85% of genetic counselors in the field (Zahm, 2010; Zahm 2009) or what encourages some of them to thrive in exceptional ways.

Indeed, research in the related field of psychological counseling has demonstrated that years of experience do not necessarily translate into levels of expertise (Jennings, Goh, Skovholt, Hanson, & Banerjee-Stevens, 2003; Skovholt & Jennings, 2004).

If multiple years of experience alone do not translate into an optimum developmental trajectory culminating in successful genetic counseling, what other variables might be involved in the development of outstanding genetic counselors? For example, although well-defined as a foundational factor in psychotherapy (Duncan, Miller, Wampold & Hubble, 2010), little publish research has considered the *person* of

the genetic counselor—the individual performing these broad and disparate tasks. If one envisions the "best of the best" (Jennings & Skovholt, 1999, p. 4) among genetic counselors, what might that person look like?

The concept of "expertise" or "mastery" in professional fields is not a new one. This concept has been explored within many fields, including psychotherapy (e.g., Skovholt & Jennings, 2004), social work (e.g., Nilsson, Ryan & Miller, 2007), as well as in health-related fields such as nursing (e.g., Adams et al., 1997; Benner, 1982), and physical therapy (e.g., Jensen, Shepard, Gwyer & Hack, 1992), among others. Although terminology and definitions used to define the concept of what it means to excel in a particular profession vary widely across studies, clearly it is one of interest across allied medical and counseling disciplines.

Research in those fields has suggested that personal characteristics as well as personal and professional experiences play a role in the professional development of "best of the best" practitioners. It is not unreasonable to suggest that the same may hold true within the field of genetic counseling.

However, no published research has yet described the characteristics of "master genetic counselors," or whatever terminology the profession ultimately chooses as best describing the concept. Still, beginning to identify defining characteristics of master genetic counselors contributes to effective counselor education as well as beginning to delineate the trajectory of professional development from novice to expert (Skovholt & Ronnestad, 1992a; Zahm, 2009). In turn, understanding optimal professional development of genetic counselors can inform best practices in the field, and contribute to development and evaluation of professional models underlying genetic counseling.

Such models of professional development provide a theoretical basis from which to design research and compare results across studies (Zahm, 2009).

One way to begin to define what it means to be an exemplary genetic counselor is by studying clinicians who have been identified as outstanding by their peers. To paraphrase Jennings and Skovholt who conducted similar studies defining the characteristics of highly regarded psychotherapists (1999, p. 4): We believe that a considerable amount can be learned about potentially efficacious genetic counselor characteristics by studying well-regarded genetic counselors.

The aim of the present study was to do just that. This investigation considered the *person* of the genetic counselor and what it takes to be successful--indeed, what might be involved in becoming *expert*--in that role. Genetic counselors often engage their patients to tell their stories in order to understand the context of their counseling. This investigation invited distinguished genetic counselors, recommended by their peers, to tell us about themselves, their professional stories, and their views of their work and the profession. The purpose was to begin to define the characteristics of exemplary genetic counselors. The study considered what it takes to be an “expert” or “master” genetic counselor. As such, the study sought to understand more fully the personal qualities and professional skill sets exemplary genetic counselors bring to their work, and it begins to define the meaning of “expertise” as a clinician in genetic counseling. This study focused on the question: What are the personal characteristics of genetic counselors who are considered outstanding by their peers?

Chapter 2

Literature Review

Paralleling the multiple threads of the genetic counseling encounter described in Chapter 1, any study of the characteristics of master genetic counselors intertwines with the historical context of the profession (Stern, 2009), as well as with 1) theories of professional development, 2) the concept of "expertise", and 3) the counselor as a significant variable within the genetic counseling interaction. Because work in these areas is just beginning to be developed within genetic counseling, this literature review considers, and also extrapolates from salient studies and theories in related helping and medical professions.

Seeking Mastery in Genetic Counseling

A handful of studies (e.g., Runyon et al., 2010; Zahm, 2010) have empirically investigated aspects of genetic counselor professional development. However, to date, no published studies have specifically explored optimal development of genetic counselors nor the characteristics such genetic counselors might bring to their practice. Thus, the characteristics of an "expert" or "master" genetic counselor remain elusive. Searches on MedLine, PubMed, and PsychINFO, combining the words "genetic" "counselor" or "counseling" with the terms expert, expertise, master, professional development, professional growth, professional identity, career, competence, role, practice, characteristics, personal, socialization, practice, training, education, and novice yielded no published investigation of expertise in genetic counselors.

One result does purport to discuss “ideal genetic counseling” (Rantanen et al., 2008, p. 445). For that study, investigators analyzed 56 international guidelines governing genetic counseling, concluding that “the ideal counselor was seen as someone who has good knowledge of human genetics and at the same time is an empathic person, whose communication is clear and who realizes the special situations that patients are facing” (p.449). However, despite the use of the word “ideal” in their title, the authors’ concluding description seems more akin to basic competencies [cf. American Board of Genetic Counseling (ABGC), Practice Based Competencies, (www.abgc.net)] than a proposal of “ideal” as it might apply to expertise.

The lack of published reports on master genetic counselors concurs with Zahm’s (2009; 2010) literature searches regarding the developmental process of genetic counselors in general. Zahm (2010) concluded that genetic counselor professional development has not yet been systematically explored. She notes, “There are few definitive answers about how exactly genetic counselors develop professionally, continue growing and thriving in the field and avoid early departure from the field due to burnout and or other contributing factors” (Zahm, 2010 p. 354). [Zahm (2009) subsequently conducted an unpublished study on genetic counseling development that is summarized later in this review.]

Genetic Counseling Literature Related to Professional Development

Few published articles within the genetic counseling professional literature inquire directly about professional development, although publications in the past few years may suggest a growing trend. The available studies show that personal and professional experiences impact genetic counselors’ development (McCarthy Veach et

al., 2002b) and that learning and professional growth continues beyond graduate school (Runyon et al., 2009).

One of the first investigations of professional development of genetic counselors inquired about "defining moments" described as "personal experiences or events that lead to a further realization of themselves as genetic counselors" (McCarthy Veach et al., 2002b, p. 277). Based on previous research in counseling psychology (Skovholt & McCarthy, 1988), the investigators invited members of the National Society of Genetic Counselors (NSCG) to describe personal or professional experiences that had a significant impact on their sense of themselves as genetic counselors. Seventeen participants provided 15 papers describing the powerful impact these experiences had on "their sense of self as genetic counselor practitioners, educators, researchers and policy makers" (p. 278). Their accounts include the impact of experiences with clients, personal grief and loss, ethical dilemmas, as well as "proactive approaches" to professional development that led to new experiences. The investigators conclude that professional development is on-going. Defining moments can happen at any time, and often carry an emotional impact that leads to discovery of personal strengths the genetic counselors may not have recognized in themselves. Further, they note that personal and professional experiences are interconnected and can influence each other in a fluid way (McCarthy Veach et al., 2002a, b). They also describe the necessity of self-reflection in order to grow from these experiences (McCarthy Veach et al., 2002a,b).

More recently, Runyon et al. (2009) extended the literature on professional development in genetic counseling by conducting an investigation of genetic counselors' perceptions of their post-degree learning. As part of the survey, they asked participants to

respond to two open-ended questions regarding what they have learned about themselves in their practice as a genetic counselor, and what advice they would offer to genetic counselors just beginning their careers. Of the 185 participants who responded to the questions, more than half had more than six years experience.

Using an interpretative content analysis, the authors (Runyon et al., 2009) extracted major themes of lessons and advice within each of three realms--Intrapersonal, Interpersonal and Professional.

Intrapersonal themes represented lessons learned from professional and personal experiences (Runyon et al. 2009) and how their own characteristics affect their work. Counselors learned the importance of self-efficacy, to assess their own abilities and to set realistic expectations of themselves (Runyon et al., 2009). Some counselors in the sample reported surprise at their confidence and personal strength in difficult situations, while others highlighted the importance of supportive colleagues. Setting limits on perfectionism was also related to increased self-efficacy (Runyon et al., 2009).

The researchers (Runyon et al., 2009) found a synergistic relationship as genetic counselors' personal and professional lives mutually influenced each other, and that there were sometimes discrepancies between the two. Lessons learned that emerged within this theme included letting go of control. This theme included genetic counselors learning lessons around open-mindedness and acceptance of other's points of view, as well as managing their own biases, values and opinions. Further, genetic counselors reported learning to accept that some things are uncontrollable (Runyon et al., 2009).

In light of their work with patients, genetic counselors also felt an appreciation for their own lives (Runyon et al. 2009). Intrapersonal themes reflected the importance of

creating meaningful relationships with patients, the importance of empathy, and of making a difference in patients' lives (Runyon et al., 2009). Acceptance of uncertainty and accepting that one cannot know everything were prominent themes. The intrapersonal theme also contained descriptions of some participants' realization of the importance of having a commitment to lifelong learning.

In the Interpersonal realm, the authors (Runyon et al., 2009) reported that genetic counselors felt they gained a deeper understanding of the process of genetic counseling on the job. Themes in this area included the meaningfulness of their relationships and empathy with clients, including managing patients and their own difficult emotions, and the importance of "presence" (Runyon et al., 2009, p. 377). The genetic counselors also reported that they became more aware of their own thoughts and feelings and gained permission to not know everything. Lessons learned about uncertainty and ambiguity were prominent Interpersonal themes.

Themes in the realm of Professional lessons revolved around workplace satisfaction and dissatisfaction as well as exploring new professional avenues in genetic counseling that participants found exciting (Runyon et al., 2009). Participants learned lessons about their own characteristics in the work setting and in working with patients.

Runyon, et al. (2009) also asked respondents what advice they would give to genetic counseling students just beginning their careers.

Participants' recommendations for new genetic counselors within the Intrapersonal realm highlighted the importance of self-care. More experienced practitioners recommended developing healthy cognitions, such as managing self-expectations and developing realistic expectations of their sessions. Advice also included

developing self-confidence, and recognizing their expertise. Participants also advised developing a balanced life, including work/home boundaries, a multi-faceted identity, and avoiding over-involvement by balancing empathy with boundaries (Runyon et al., 2009),

Interpersonally, experienced genetic counselors encouraged their new colleagues to deeper their interaction with clients by responding to the psychosocial realm, to be open-minded, and attend to the patient/client interaction (Runyon et al., 2009). They recommended flexibility and the importance of cultivating empathy as a powerful skill. Additional advice involved developing positive relationships with the people around them.

In the Professional realm, the participants advised new genetic counselors to find a "fit", get help when necessary, anticipate obstacles, and try new things (Runyon et al., 2009).

Work setting—particularly in terms of access to supervision and case load-- may also play a role in professional development (James, Worthington, & Colley, 2003). These investigators conducted a 34-question questionnaire study of (Australian and New Zealander) genetic counselors' perceptions of their day-to-day activity aimed at documenting genetic counselors' roles and resources. Professional Development was one of five main areas they considered. Questions about professional development included type and frequency of contact with other genetic counselors and geneticists, type, frequency and physical access to professional affiliations, conference attendance and financial support from employer. A total of 76 questionnaires were returned, resulting in a commendable response rate of 71 percent. Unfortunately, as the authors noted, (James,

Worthington, & Colley, 2003) their questionnaire did not allow for extensive statistical analysis.

Descriptive data, however, showed that genetic counselors have strong interest in professional development (James, Worthington, & Colley, 2003) and extended previous research articulating the importance of supervision for genetic counselor growth and development (e.g., Kennedy 2000a,b; Weil, 2000). However, in spite of genetic counselors' interest, James et al. (2003) found a lack of adequate—and in some cases required—supervision. Specifically, for genetic counselors in metropolitan areas, heavy caseloads interfered with time for supervision, while those working in rural areas did not have adequate access to appropriate supervisors. The authors noted this was especially true even counselors still in training who tended to be working in the rural Australia and New Zealand, where their study was conducted.

Consequently, James et al. (2003) advocated for employers to provide for adequate access to appropriate supervision as well as administrative support to allow genetic counselors adequate time to perform their primary roles of providing patient consultation.

The Evolving Face of Genetic Counseling

The limited literature on genetic counselor professional development and the dearth of literature on what might be considered optimal development is not particularly surprising, considering the developmental stage of the profession. What may have been considered excellence, or pinnacle professional development early in the field's developmental history (Kessler, 1997; Resta, 2006; Stern 2009) may not resonate with today's perspective as professional models of the field mature (Fox, Weil, & Resta, 2007;

McCarthy Veach, Bartels & LeRoy, 2007; Resta, 2006). Although the phrase "genetic counseling" was coined in the 1940s testing for genetic disease was very limited and even the number of number of human chromosomes was not yet known (Resta, 2006).

Genetic counseling as a profession began in the 1970s as an adjunct to clinical genetics (Resta, 2006), particularly reproductive genetics (Biesecker, 1998; Weil et al., 2006), and within the context of the women's rights movement and feminist reproductive health (Stern, 2009). At that time, human genetic knowledge was in its infancy (Resta, 2006), and thus a primary goal of genetic counseling was "to educate about etiology and recurrence risk and to assist clients in reproductive decision-making" (Bernhardt, Biesecker & Mastromarino, 2000, p. 189). As pioneer genetic counselors started from scratch to develop a profession just a few decades ago (Stern, 2009), initial models for the profession were somewhat dichotomous in delineating either one of teaching or one of counseling (Kessler, 1997). While there is some overlap in the role of teacher and the role of counselor, excelling in one may differ from excelling in the other.

Steeped in non-directiveness, early research trajectories generally followed a "teaching" metaphor, consequently focusing on "educational" outcome measures such as information provision (Bernhardt et al., 2000; Biesecker, 2003; Davey et al., 2005; Pilnick & Dingwall, 2001), patient recall, understanding of medical and genetic information, content of sessions, reproductive plans and behavior (Berkenstadt, Shiloh, Barkai, Katznelson, & Goldman, 1999). In parallel with genetic counseling's foundational adherence to the psychotherapeutic influences of non-directiveness and other Person-Centered tenets (McCarthy Veach, LeRoy, & Bartels, 2003; Weil, 2000), research focused, for the most part, on the client, although some research has considered

counselor variables such as the way information is presented (Shiloh, Avdor, & Goodman, 1990) and what aspects of genetic counselor behavior clients found most and least helpful (McCarthy Veach, Truesdell, & LeRoy, 1999).

More recently, and as the field has evolved, the *counseling* and *process* aspects of genetic counseling have gained more attention in the professional literature (e.g., Abrams & Kessler, 2002; Matloff, 2006; McCarthy Veach et al., 2002a; Resta, 2002). In a comprehensive survey of the genetic counseling literature Pilnick and Dingwall (2001) called for identifying the counseling components of the *process* of genetic counseling and the *factors* which influence them. And some studies have begun to identify personal characteristics of the genetic counselor, such as dedication and interest in patients' personal problems (McCarthy Veach et al., 1999), as pertinent to client satisfaction. Others have explored differences in counselor communication styles (Biesecker, 2001; Biesecker & Peters, 2001; Meiser, Irle, Lobb, & Barlow-Stewart, 2008; Wang, Bowen, & Kardia, 2005). This research provides some basis for study of the person of the genetic counselor as a factor in genetic counseling sessions.

Simultaneously, the earlier, more narrowly defined paradigms of genetic counselors' role have been deemed insufficient in describing what genetic counselors actually do, the help they provide, and the knowledge they possess (Resta, 2006). Thus, the field's developmental process has lead genetic counselors to explore, discuss and reevaluate defining models underlying their work (Biesecker, 1998; Callanan, 2006; The National Society of Genetic Counselors' Definition Task Force, 2006). This on-going developmental task has prompted proposals of more comprehensive models of genetic counseling practice, such as the Reciprocal-Engagement Model (McCarthy Veach et al.,

2007). The Reciprocal-Engagement Model (REM) based on data generated during a consensus meeting of North American genetic counseling program directors, encompasses genetic counselors' fundamental beliefs, goals, strategies, and behaviors that characterize genetic counseling practice (McCarthy Veach et al., 2007; LeRoy, McCarthy Veach, & Bartels, 2010,). Importantly, the REM model acknowledges the interaction and "mutual influences" (McCarthy Veach et al., 2007; LeRoy, McCarthy Veach, & Bartels, 2010, p. 3) among five key tenets, or fundamental beliefs, which include both the client *and* the genetic counselor. Further, the model explicitly centers genetic counseling within the genetic counselor-patient relationship which "comprises the conduit for the processes and outcomes of genetic counseling" (LeRoy et al., 2010, p. 3). According to the REM model, it is within the relationship that key tenets involving the importance of genetic information, support for patient autonomy and patients' emotions and resiliencies manifest [i.e., genetic counseling happens within the relationship between the client(s) and the counselor]. This interactive and systemic view of the profession is necessary and vital for a number of reasons.

Perhaps most pertinent for this review is its acknowledgement of, respect for, and consideration of the "person of the genetic counselor" (LeRoy et al., 2010, p. 2). Following years of being overshadowed by developmentally appropriate--and sometimes exceptionally literal--nondirectiveness (Beckendorf, Prince, Rose, DeFina, & Hamilton, 2001) --the *person* of the genetic counselor and his or her influence in the process of the genetic counseling experience is now emerging. And as will be seen in borrowing from related fields (e.g., Duncan et al., 2010), the person of the genetic counselor may be an important and thus far overlooked component of exceptional genetic counseling.

The Person of the Genetic Counselor

There are very few published studies focusing on personal characteristics of genetic counselors. This can be significant in that personal characteristics can play a role in ethical dilemmas (Bower, McCarthy Veach, Bartels & LeRoy, 2002; McCarthy Veach, LeRoy, & Bartels, 2001) and clinical practice (Abrams & Kessler, 2002; Marks, 1993; McCarthy Veach et al., 2002c; Weil, 2003). Personal values of genetic counselors are also important within sessions (Pirzadeh, McCarthy Veach, Bartels, Kao, & Leroy, 2007). Exploring characteristics of genetic counselors whose professional work is well-respected by their peers is one way to further understanding of "expertise" in genetic counseling

In his discussion of the central ethos of genetic counseling, Weil (2003) notes "…this is a fundamentally humanistic undertaking" (p. 207). While his focus is on the psychosocial importance of genetic counseling to the *client*, it can be argued that the human variable of the *genetic counselor* is of equal importance in the interactive encounter (McCarthy Veach et al., 2007). As will be seen, this concept has found a solid base in related fields (e.g., Duncan et al., 2010; Orlinsky et al., 2005; Rønnestad & Skovholt, 2003).

As Zahm (2009) and others (e.g., Jennings et al., 2003) notes, "how one develops and practices professionally are related to factors beyond years of experience" (p. 354). Indeed, research in the field of psychological counseling has shown that years of experience alone do not necessarily correspond with expertise (Jennings et al., 2003).

Understanding the characteristics that may contribute to the "best of the best" genetic counselors may illuminate genetic counselor education, address attrition, and

provide goals and trajectories for positive development (Rønnestad & Skovholt, 2003; Skovholt & Ronnestad, 1992a,b), and ultimately foster patient care and best practices.

Despite the lack of studies directed toward identifying characteristics of "expert" or "master" genetic counselor, some published work hints at what may be involved. Bodies of work on the impact of personal experience, valued attributes, and the salience of the counseling relationship within genetic counseling offer clues to the portrait of what might constitutes a "master," "seasoned," or "expert" genetic counselor.

Research evidence strongly supports the importance of the therapist in the psychotherapy encounter (Duncan et al., 2010). Interestingly, the importance of the therapist in these studies of psychotherapy came about despite efforts to standardize treatment protocols and to control for differences in individual therapists (Lambert & Okiishi, 2006). Thus, even with similar "scripts", protocols and other controls, individual differences remained quite salient.

Hubble, Duncan, Miller and Walpold (2010) conclude, "Available evidence documents that the therapist is the most robust predictor of outcome of any factor ever studied" (p. 38). Consequently, what patients experience in psychotherapy depends largely on the characteristics and qualities of their therapists (Grawe & Parks, 1994; Orlinsky 2005). These findings indicating the salience of therapist characteristics echo earlier results in the medical field, such as a meta-analysis showing significant correlations among medical providers' behaviors and characteristics and patients' medical outcomes (Hall, Roter, & Katz, 1988).

The genetic counselor as a defining variable. Although studies of genetic counselor development are rare, a growing body of research supports the salience of the

genetic counselors' personal characteristics (Abrams & Kessler, 2002; McCarthy Veach et al., 2002b; Pirzadeh et al., 2007; Runyon et al., 2010; Weil, 2003). Much of this evidence has emerged indirectly through studies of genetic counselors' personal values (Abrams & Kessler, 2002, McCarthy Veach, Bartels, & LeRoy, 2002b; Pirzadeh et al., 2007) and of compassion fatigue (Benoit et al., 2007; Injeyan et al., 2011; Udipi et al, 2008).

In a qualitative, focus-group study regarding compassion fatigue, for example, Benoit, et al., (2007) suggested that personality traits, such as the desire to be liked, perfectionism, and need for control may stem from personality traits that could put genetic counselors at risk for compassion fatigue.

In a follow up study directly focusing on personality traits, Injeyan et al. (2011) studied two personality traits in relation to risk of compassion fatigue in genetic counselors. They found that an external locus of control and low dispositional optimism are related to a higher risk of compassion fatigue. These investigators survey 355 genetic counselors and used correlational analysis and step-wide logistical regression to assess optimism and locus of control in the presence of other variables such as length of years in practice, number of genetic counselor colleagues in the workplace, and graduate training about compassion fatigue.

Significant for the present review is the direct finding that personality traits play a very important role in genetic counselors' work life. The findings provide evidence of the impact of counselor characteristics on genetic counseling work. As the authors point out, research has shown that optimists and pessimists react differently when faced with stressors, and this influences coping style (Injeyan et al., 2011). Optimist will persist,

while pessimists will avoid or blame themselves. "Optimistic counselors, rather than giving up, will problem-solve, seek social support, engage in self-reflection" (Injeyan et al., 2011, p. 533).

Locus of control relates to attribution style and one's belief in their capability to control outcomes. Injeyan et al. (2011) found that an internal vs. external locus of control served as a buffer against compassion fatigue. The authors speculated, therefore, that genetic counselor with an internal locus of control "perceive themselves as having control over the outcomes and are more likely to use active coping mechanisms associated with better adjustment to stress (Injeyan et al., 2011, p. 533). Further, the investigators speculate, "Genetic counselors with an internal locus of control may derive more satisfaction from their attempts to assist patients because they interpret positive counseling outcomes to be the result of their own efforts" (Injeyan et al., 2011, p. 533).

Based on this study, one might hypothesize that master genetic counselors tend to be optimistic and with an internal locus of control. However, their internal locus of control may require balancing with letting go of perfectionism and control as well as realistic expectations (Runyon et al., 2009).

Another body of research also supports the idea that genetic counselors' personal characteristics play a role in their work. Studies of genetic counselors' personal *values* and their influence in genetic counseling has growing empirical support (e.g., Abrams & Kessler, 2002; Bowers et al., 2002; Lega et al., 2005; McCarthy Veach et al., 2001, Pirzadeh et al., 2005). Both Lega et al. (2005) and Pirzadeh et al., (2005) found that genetic counselors highly value benevolence (concern for others), self-direction (independence) achievement and universalisms (protecting the welfare of all). Lega

looked at genetic counseling students. Pirzadeh's national sample of 292 genetic counselors who took an on-line survey, ranged from individuals with just three months of experience to those with more than three decades. Results indicated no significant relationship between either age or years of genetic counseling experiences across the 11 values studied. Thus, this research indicates the importance of at least some counselor characteristics, but that values do not vary across experience levels. Pirzadeh et al. (2005) poses questions of whether personal values affect who enters and stays in the genetic counseling, and how values may influence the process or outcomes.

Another series of studies provide evidence of differences in genetic counselors' communication styles, and the investigators have attributed differences in sessions to the genetic counselors rather than to the client. For example, in a study of communication in genetic counseling sessions, Ellington and colleagues (Ellington et al., 2006) attributed variation to the genetic counselor rather than to differences in client characteristics. In their analyses of 167 sessions conducted by three certified genetic counselors, they identified four communication patterns based on content and ratios of talk within the sessions. Occurrences of the four communication patterns occurred with all three counselors. However, for each counselor, one pattern occurred more frequently than the others, seeming to indicate a "distinct communication style" (Ellington et al., 2006, p.185.) For example, for one counselor, the pattern called "biomedical question and answer" occurred with more than 65% of clients, while the so-called "client focused biomedical" communication pattern occurred with nearly 60% of another counselors' clients. The four communication patterns were more evenly divided across clients for the third counselor. As with studies within psychotherapy discussed previously in this

chapter, differences in communication style were found despite a standardized research protocol and similar levels of genetic counseling experience among the counselors.

The Importance of the Counseling Relationship. The counseling relationship has long been considered central to genetic counseling (Baker, Schuette, & Uhlmann, 1998; Evans, Bergun, Bamforth, & MacPhail 2004; McCarthy Veach et al., 2003, 2007; Rantanen et al., 2008). A large body of research within the field of psychotherapy has strongly validated the importance of the working alliance in that related field. For example, evidence regarding the power of the working alliance—the partnership between client and counselor--is reflected in the findings of more than 1,000 studies (Hubble et al., 2010; Orlinsky, Ronnestad & Willutzki, 2004).

"Assuming that the personal characteristics of the therapist influence the quality of the therapeutic alliance, it may be useful to understand more fully the qualities effective therapists bring to their work" (p. 3), Jennings and Skovholt (1999) hypothesized in their work regarding master psychotherapists. Their statement would seem to hold equally true for genetic counselors.

Genetic counseling theories underscored the importance of the working relationship between patient and genetic counselor (McCarthy Veach et al., 2007). Additionally—and importantly--several studies which considered genetic counseling from the clients' perspective also offer support for the saliency of the genetic counselor and the working relationship in genetic counseling interactions.

For instance, one study described 28 former genetic counseling clients' expectations of the genetic counseling relationship (McCarthy Veach et. al., 1999). In discussing their in-session affect the former clients referred to personal characteristic of

the counselors, including their warmth, caring, knowledge, and explanation of complicated information (McCarthy Veach, et. al., 1999).

McAllister and colleagues (2008) conducted a qualitative, grounded theory study investigating what process attributes are valued by patients and genetic counseling service providers. They conducted seven focus groups with 33 participants and 19 individual interviews. Participants identified five highly valued attributes, one of which was the quality of the counselor-patient relationship and another being time to talk. Counselor qualities identified as important included social competence, flexibility, compassion, empathy, and responsiveness.

In a study focusing on the "value" of genetic counseling, Bernhardt et al. (2000) found that both clients and counselors considered the interaction and "connecting" between genetic counselor and client to be primary indicators of success in genetic counseling. Counselors reported providing support by listening and validating client concerns, empowering clients, and facilitating their decision-making. Clients perceived support as encouragement, kindness, positive stories, and feeling cared for by the counselor. Additionally, genetic counseling clients identified the "supportive component" (p. 193), including understanding of emotions, as especially helpful and as distinguishing genetic counseling from a doctor's appointment.

In addition, some investigators have reported individual differences in the type of counseling relationships genetic counselors create (Ellington et al., 2006; Ellington et al., 2005). Other researchers have identified significant differences among individual geneticists and genetic counselors in facilitating understanding, active involvement,

partnership building, and addressing emotional concerns (Lobb, Butow, Barratt, Meiser, & Tucker, 2005).

Theories of Professional Development

Clearly genetic counselors grow in their professional capacity over time (McCarthy Veach et al., 2002b). For example, comments from participants at the 2003 NSGC Annual Education Conference strongly suggest that genetic counselors change and develop over time (Weil et al., 2006), as a consequence of life experiences (McCarthy Veach et al, 2002b), and from on-the-job learning (Runyon et al., 2009).

In order to understand the "best of the best" genetic counselors, it is necessary to consider professional development. However, given the paucity of research concerning genetic counselor professional development, and no research on what constitutes expertness or master provision of genetic counseling, it is appropriate to consider research findings in related fields.

Related fields have seen an increase in literature on professional development, and by extension, on the characteristics of master practitioners in those fields. These studies have stimulated the creation of models of professional development, and expertise; those models, in turn, provide a theoretical basis from which to design additional research and to compare results across studies (Zahm, 2010). Although genetic counseling is its own unique health profession (McCarthy Veach et al., 2002a), extrapolating from related fields is an appropriate means of exploring uncharted research territory within genetic counseling and to begin to develop developmental theory for the profession. Such extrapolation is particularly relevant since ongoing professional development for practicing genetic counselors is critical in maintaining best practice vis a

vis skills and knowledge (Katsichti, Hadzipetros-Bardanis & Bartsocas, 1999; McCarthy Veach et al., 2007). In fact, the ABGC identifies continued professional growth and lifelong learning as one of 27 practice-based competencies for genetic counselors (http://www.abgc.net.) Thus, a general understanding of professional development is necessary in order to understand professional expertise and to identify master genetic counselors.

Therefore, the following section contains a summary of published literature on: 1) theories of professional development, 2) development of expertise or mastery in the allied fields of nursing, social work, physical therapy and counseling, and 3) results of the relatively few investigations of professional development in genetic counseling.

An in-depth examination of the extensive literature on professional development in related fields is beyond the scope of this chapter. However, researchers have suggested certain common features of the concept of professional development that are applicable to understanding exemplary development. For example, professional development implies change that is organized systemically and occurs over time (Ronnestad & Skovholt, 2003).

The Dreyfus Model.

Seminal studies of expertise in psychotherapy (e.g., Skovholt, Hanson, Jennings & Grier, 2004), social work (e.g., Fook, Ryan, & Hawkins, 2000), physical therapy (e.g., Jensen, Gwyer, Shepard & Hack, 2000) and nursing (e.g., Benner, 2000b; Benner, Tanner, & Chesla, 1992) are based on a model of professional development developed in 1986 by philosopher Hubert Dreyfus and his brother Stuart, a computer scientist (Dreyfus & Dreyfus, 1986). In their model of development, learners progress from detached,

abstract and consciously analytical thinking and responses toward internal, skilled behavior based on unconsciously and intuitively recognizing similarities between current and previous experience (Dreyfus & Dreyfus, 1986). Fook et al. (2000) note that in the Dreyfus Model, this is a distinction between “knowing that” and “knowing how.” Understanding of knowledge based on facts and rules gradually becomes more “practice-based knowledge derived from experience” (Fook et al., 2000, p.9).

Because the Dreyfus model is based on the authors’ study of adult learners in a number of occupations, it is considered applicable to any practitioner developing skills in unstructured problem situations (Fook et al., 2000). According to the theory, with concrete experience, skilled behavior becomes increasingly based on “intuitive recognition of similar situations” (Fook et al., 2000, p. 9). As a practitioner progresses, rules and decision-making hierarchies become subsumed by her or his own internal knowledge. Because genetic counseling often presents “unstructured problems,” and because genetic counselors undergo intensive and progressive training and acquisition of knowledge, it is reasonable to view genetic counselor professional development according to the broad model proposed by Dreyfus and Dreyfus (1986). Based on that model, it is also reasonable to assume that some genetic counselors would progress to the highest level of thinking and practice described by the model.

In order to describe optimal development, it is necessary to understand the process. According to their five-stage model (Dreyfus & Dreyfus, 1996) each stage of development is qualitatively different from and builds on previous stages. Originally based on studies of expert chess players, air force pilots, and army commanders and tank drivers, the Dreyfus Model views expertise as based on learning through experience and

through reflecting on that experience. As they move through the stages and reflect on their work, practitioners' thinking about their work moves from abstract to concrete, and from specific to holistic (Dreyfus & Dreyfus, 1996). Practitioners also move from detached observers to involved practitioners. Thus, the Dreyfus Model (Dreyfus & Dreyfus, 1996) supports *experience based in context* as a prerequisite to progressing from novice to expert. As with other professionals, this process seems compatible with the training and experience of genetic counselors.

Results of a study of expert nurses support this aspect of the Dreyfus model. In their investigation of expert nurses, Benner et al. (1992) concluded, "They learn to apply previous experience, shift from reliance on analytic, rule-based cognition to more 'intuitive' thinking, and from seeing situations as based on a compilation of equally relevant bits to an increasing complex whole in which certain parts are relevant' (p. 14).

The Dreyfus Model (1986; 1996) contends that learners move through five stages on their way to expertise in a particular domain: novice, advanced beginner, competent, proficient and expert. As individuals progress through each stage, they move from more external to more internal rules for guiding behavior (Skovholt et al., 2004). As they move through the cumulative stages, their cognitions about their work move from abstract to concrete. That is, they begin by relying on rules and guidelines, and with experience and reflection, gradually grow into an internalized way of knowing and responding (Skovholt et al., 2004).

The five stages presented next are based on Dreyfus and Dreyfus (1986) and follow closely from the succinct description of Benner's Stages of Clinical Competence for Nurses (Benner, 2000a,b; Benner, Tanner, & Chesla, 2009; Saver & Habel, 2009) and

from Skovolt et al.'s (2004) description of therapists. The model has since been applied to multiple counseling and health care fields (see the following sections).

Stage 1: The Novice Stage. Beginners have little experience with the situations in which they are expected to perform (Saver & Habel, 2009). They rely on rules that they apply universally, with little regard for a specific situation. Skovholt et al. (2004) likened their behavior to student counselors who cling "tightly to one counseling theory with little regard for the particular issues presented by their clients" (2004, p. 10). Because rigid rules cannot adequately fit every actual situation, a novice's behavior in the clinical setting is limited and inflexible (Benner et al., 2009; Saver & Habel, 2009).

Stage 2: The Advanced Beginner. With more experience than the novice, advanced beginners are better able to integrate the specific contexts of their clients with their theoretical knowledge (Fook, Ryan, & Hawkins, 1997). Performance improves with experience and practitioners begin to discern the recurring, meaningful components of particular situations. They begin to formulate guidelines on which to base their actions (Benner et al., 2009; Saver & Habel, 2009). Although they have gained knowledge and skills, advanced beginners still lack many in-depth encounters with similar patients. Benner et al. (2009) consider this phase to occur during nursing graduates' first job. Dreyfus and Dreyfus (1996) describe this period as one of feeling overwhelmed by the complexity of the skills and exhausted by the effort necessary to recognize relevant elements and remember a growing sets of more complicated rules.

Stage 3: Competence. "People learn, or are taught, to adopt a hierarchical procedure of decision-making" (Dreyfus & Dreyfus, 1986, p.24) during the Competence Stage. Counselors in the Competent Stage integrate theoretical knowledge with learned

experience and become better able to determine which factors presented by clients may be the most salient (Skovholt et al., 2004). As Benner et al. (2009) noted, nurses at this stage begin to see their actions in the context of long-range goals or planning. Although they lack the speed and flexibility of proficient nurses, they grow a feeling of mastery and can rely on advanced planning and organizational skills. Due to their increased sense of understanding which factors are important, along with growing recognition of patterns within clinical situations, practitioners need to examine fewer options prior to making clinical decisions (Benner et al., 2009; Saver & Habel, 2009). At this stage, nurses feel more personally and emotionally involved in outcomes based on their decisions compared to the rule-following stance of the earlier stages (Dreyfus & Dreyfus, 1986). During this period of development, learners may feel they are on an emotional roller coaster, and due to the fear of risk and responsibility may become stagnated, leading to withdrawal (Dreyfus & Dreyfus, 1986).

Stage 4: Proficient. This stage is “marked by the ‘intuition’ experts in a domain seem to share” (Skovholt et al., 2004, p. 11). At this stage clinical situations are viewed as wholes rather than parts, and there is a nuance understanding of the situation that guides performance. The Proficient stage (and also the final stage of Expert) “are characterized by a rapid, fluid, involved kind of behavior that bears no apparent similarity to the slow, detached reasoning of the problem-solving process” (Dreyfus & Dreyfus, 1986, p.27). Practitioners are able to modify plans in response to changing circumstances or different events. They can react to internally recognized patterns without needing to break them into their components, allowing for a more holistic perception of a situation.

Stage 5: Expert. The final stage is that of expert. At this level, the learner has grown through the previous stages, and has reflected on his or her accumulated experience (Dreyfus & Dreyfus, 1986). Understanding is effortlessly based on experience and critical reflection. "At this stage the counselor has long since let go of externalized textbook theories…to guide his or her actions and is instead operating from an internal, personalized, theory of counseling developed from years of practice, experience, reflection and intuition" (Skovholt et al., 2004, p. 11). Their grasp of a situation is intuitive, and they "holistically and effortlessly understand and use patterns and situation" (Skovholt et al., 2004, p. 11). They can "intuit" (Skovholt et al., 2004, p.11) and "know what needs to be done" (Saver & Habel, 2009), based on a well-developed ability to recognize relevant problems and options. Some researchers call this ability "craft knowledge" (Shepard, Hack, Dwyer & Jensen, 1992, p. 751) or "clinical knowledge" as opposed to formal knowledge, while others view it as an intuitive grasp of knowledge (Benner et al., 1992).

Dreyfus and Dreyfus (1986) maintain experience in real situations is necessary to develop high level skills and that interaction between theory and practice is necessary for acquiring expert skills. They also differentiate between "rule-based reasoning" and "intuition," while stressing that "intuition does not constitute 'wild guessing or supernatural inspiration'" (p. 38). Rather they define intuition as an ability to differentiate between different sensory inputs and to respond accordingly, and they further note that such ability is explainable in physiological terms. They assert that "Theory and practice intertwine in a mutually supported process [and]…. only if both are cultivated and appreciated can full expertise be realized" (p. 30).

Rønnestad and Skovholt's model of professional development.

In searching for explanatory models of expertise in counseling and psychotherapy, researchers found limits to the strict focus on cognitive perception in model such as that of Dreyfus and Dreyfus (1986); they identified a need to consider other variables such as the working alliance and developmental paths, and to consider the importance of self-reflection (Skovholt, Ronnestad & Jennings, 1997). Based on cross-sectional and longitudinal qualitative studies of 100 counselors and therapists, Rønnestad and Skovholt (2003) developed a model of development similar to the Dreyfus model and specific to counselor development. They described counselor development as occurring in six phases: lay helper, beginning student, advanced student, novice professional, experienced professional and senior professional. They conducted their study at a time when there was little literature on professional development in the counseling professions (as is currently the case in genetic counseling).

Rønnestad and Skovholt (1992b) interviewed 100 American counselors and therapists at different levels of experience. Their sample included two student groups and three post graduate groups of practitioners (averaging 5, 15 and 25 years of professional experience). The researchers selected eight a priori topics for organizing their interview data within each cohort. Their data analysis resulted in an 8-stage model of professional development, which they later condensed to six "phases." After the initial analysis, the researchers then "took a different approach to [their] analysis" by making an effort to disregard the apriori structure, and reanalyzing the interviews at "a higher level of inference" (Rønnestad & Skovholt, 2003 p. 9). They presented the results of this six-year study in three ways: as a stage model of development, as a themes of development,

and as a process model of development and stagnation (Skovholt & Rønnestad, 1992a, 1992b; Rønnestad & Skovholt, 2003). The investigators further analysis of the most senior therapists will be discussed in detail below.

The descriptions of Ronnestad and Skovholt's model of development outlined below are taken closely from the succinct descriptions in their 2003 publication. This review will focus more on the professional phases of development than on the student phases.

Phase 1: The Lay Helper Phase. At this stage the untrained helper is guided by a personal theory and common sense understanding of helping others.

Phase 2: The Beginning Student Phase. Professors and educational mentors are key for learning at this stage as beginning counseling students address feelings of apprehension and anxiety, learn "easily mastered, straight-forward" (p. 12) counseling methods, and begin to learn from experiences with clients.

Phase 3: The Advanced Student Phase. Generally occurring at the end of training, the student is working in a field placement such as practicum or internship, receiving formal supervision, with the central task of functioning at a basic professional level. Internalized high standards lead to a lack of risk-taking or spontaneity in their work, with a tendency toward excessive and misunderstood responsibility. Interns may feel a juxtaposition of dependency and autonomy, and consequently face constant self-evaluation. At the same time they are critically evaluating counseling as well as role models. Although their focus is still generally external, for example, imitating models, an internal focus is developing.

Phase 4: The Novice Professional Phase. The Novice Professional cohort in Rønnestad and Skovholt's (2003) study had been practicing for an average of five years at this phase. They expressed a sense of being on their own, and a continual process of "shedding and adding" (p. 17). Sequential change during these years includes seeking validation of one's training, and "confronting professional challenges inadequately mastered" (p. 17), followed by an "intense exploration of self and the professional environment." New counselors recognize the expression of themselves in their work more and more. This experience may be positive or negative, depending on the counselor's self-evaluation. The investigators noted that freedom from constraints and an eagerness for confirmation as a professional often lead to an unexpected sense of disillusionment as new professionals confront gaps in their knowledge. At the same time, learning from clients increases. Novice professionals may feel a sense of disappointment in themselves and struggle with boundaries or issues of responsibility.

The therapeutic relationship takes on more saliency as counselors experience an increased sense of the complexity of their work and recognize the profundity of the counseling relationship. Their realizations lead to tasks such as understanding and mastering relationship issues and managing work roles and boundaries. "Contrasted with earlier skill/technique acquisition, there is a more inner-directed and autonomous character to learning the specifics of professional work at this phase" (Rønnestad & Skovholt, 2003, p. 19).

Phase 5: The Experienced Professional Phase. Authenticity and congruency are hallmarks of this phase of counselor development. Having practiced for about 15 years, professionals at this stage have broad experience. As such, their developmental

task is one of creating a counseling role which is highly congruent with their sense of themselves, including their values, interests and attitudes. Resolution of these tasks makes it possible for a counselor to "apply his/her professional competence in an authentic way" (Rønnestad & Skovholt, 2003, p. 20). Through an integration and consolidation process, experienced professionals build "consistency and coherence in their personal/professional self" (p. 20). They seek "fit" with themselves in their conceptualization and work environment, and they acquire more flexibility in their role and working styles. Counselors feel more comfortable and competent in their work and trust their professional judgment.

The saliency of the therapeutic relationship in their work continues to deepen and is often now viewed as crucial for client progress. Counselors are keenly aware of the strengths and challenges of their influence vis a vis their power, attention, expectations and personality within the therapeutic encounter. Techniques and methods are now used in a "personalized and flexible way" (p.21) rather than rigidly and mechanically.

Ambiguity is addressed as clinicians in this phase experience "a profound realization that there are no clear answers to the challenges encountered" (Rønnestad & Skovholt, 2003, p. 20). They become more aware of their strengths, limitations and responsibilities, blaming themselves less and being be able to "let go" of sessions.

Experienced professionals report that a great deal of their learning comes from their clients and from their own personal lives, emphasizing the ongoing importance of interpersonal experiences and reflection upon them. They are increasingly aware of the reciprocal influence of their personal and their professional lives.

Phase 6: The Senior Professional Phase. Practitioners at this phase are well-established in their careers and are at mid-career or beyond. The cohort in the Rønnestad and Skovholt study (2003) had practiced for a modal 20-25 years, and were approximately age 64 at the first interview, and age 74 at the second interview. Their transition to "senior professional" was not always an easy one, with some clinicians feeling the role did not fit them, or experiencing loss that can be common in this age, such as concerns about failing health and physical declines, or loss of mentors or relationships with colleagues. Some expressed regrets, and some experienced "intellectual apathy and a sense of boredom" (Rønnestad & Skovholt, 2003, p.26). However, this was not typically the case (Orlinsky & Ronnestad, 2005; Rønnestad & Skovholt, 2003).

More frequently, counselors/therapists at the Senior Professional phase remained committed to professional growth: "They generally have a sense of self-acceptance and feel satisfied with their work. They feel competent but also more modest about what they can accomplish in their work" (Rønnestad & Skovholt, 2003, p. 26). Anxiety may lessen, and comfort levels may be higher. They can easily access their repertoire of skills, feel humbled by their clients' sharing, and experience pleasure at being able to help. Mentoring the next generation of counselors was an important activity that provided professional stimulation and learning.

Overall, these models of professional development provide a theoretical from which to consider the phenomenon of expert development within genetic counseling.

Defining "Master Genetic Counselor"

Although the field of genetic counseling has considered factors which might be involved in professional stagnation, particularly in terms of compassion fatigue (Benoit et al., 2000; Injeyan et. al., 2011; Udipi et al., 2008), definitions of what it means to develop optimally are lacking.

In fact, the term to use in describing the "best of the best" genetic counselors is itself an unexplored one. As with other terminology (Stern, 2009), the field will have to decide for itself. Across related professions, the terminology and definitions are subjective and varied. A review of research within counseling, social work, nursing and other human services professions suggests that the phenomenon of "master" development is known by many different names, and has yet to be defined adequately. For example, within psychotherapy, as the term "master therapists" (Jennings & Skovholt, 1999) is used, whereas in nursing, a popular term is "expert nurses."

For the present investigation, the term "master genetic counselor" is borrowed from seminal research in psychotherapy by Jennings and Skovholt (1999). However, even these researchers acknowledge there is no agreed upon definition of "master" counselor (Jennings, et al., 2003). Synonyms such as "seasoned," "well-regarded," "considered among the best of the best among their professional colleagues" (Jennings & Skovholt, 1999, p. 8), and "Senior Professionals" (Rønnestad & Skovholt, 2003) are equally vague.

Although Skovholt and Jennings (2009) suggested using *master therapist*, only when there is "evidence of expertise," the concept of "expertise" itself is equally difficult to define adequately (Overholser, 2009; Ryan, Dowden, Healy, & Renouf, 2005) or

quantify in human-related fields, perhaps partly due to the difficulty in predicting psychological events (Overholser, 2009).

Thus, what constitutes a master genetic counselor has yet to be explored, let alone defined. Moreover, definitions in related fields are varied and vague.

Characteristics of "experts". Without question, mastery is related to expertise (Jennings & Skovholt, 1999). A great deal of research has studied expertise, beginning in the 1960s in conjunction with research on artificial intelligence and cognitive psychology (Chi, Glasser & Farr, 1988; Glasser & Chi, 1988). This early research across many domains resulted in a set of key characteristics that investigators considered applicable to multiple types of expert performance within a particular domain. [A throughout review of the extensive literature on expertise is beyond the scope of this paper. See Skovholt et al. (2004b) for a more extensive description of the history of the study of expertise as it relates to the helping professions]. Summarizing various definitions of expertise, Skovholt et al. (2004a) adopted one from psychologists Ericsson and Lehmann (1996) who define experts as those individuals who "possess a unique combination of the innate talents and the motivation necessary for the rigorous training and practice required to achieve excellence" (in Skovholt et al., 2004a, p.5).

Glasser and Chi (1988) outlined several characteristics of expert performers. Experts were concluded to: excel in their own domains due to having extensive knowledge about it: perceive large meaningful patterns within their domain, which is reflective of their cognitive organization of the knowledge ; consequently perform and solve problems faster than novices in their particular domain; see and represent a problem in their domain at a deeper level than novices; base their thinking on principles rather

than surface characteristics; build mental representation that they use to infer relationships underlying a particular situation; add constructs to the problem; and have strong self-monitoring skills.

Although these characteristics are narrowly focused on cognitions and their impact on behavior (with a lack of attention to affect), these characteristics have informed the descriptions of expertise proposed in the helping professions. For instance, within the helping professions, expertise has been described as possession of cognitive tools or skills that assist in the interpretation and application of evidence that develops over extended practice and is more sophisticated than that of novices (McCracken & Marsh, 2008; Overholser, 2009). Expertise is not simply the mastery of specific techniques (Skovholt & Jennings, 2004). Rather, experts know when to deviate from the rules (Benner, 1982); they have the ability to identify what is new and unique about a situation, and to respond accordingly, as they perceive and prioritize relevant knowledge and actions (Fook et al., 2000). Some contend "It is these procedural or process-oriented skills and values which may in fact differentiate the 'expert' from the merely 'experienced'" (Fook et al., 2000, p. 180).

In more medically-oriented fields (Shepard et al., 1992) some authors contend that experts differ from individuals in other stages of development in both their knowledge and skills and their interpersonal skills and caring. And there is evidence of this in psychotherapy as well, particularly as it relates to practitioners'' ability to create interpersonal working relationships with their clients. In one of their early reports on the cognitive, emotional and relationship characteristic of master therapists, Jennings and Skovholt (1999) offered a review of the variables demonstrated to have an impact on

successful psychotherapy—the so called “common factors” (Duncan et al., 2010). These factors include client variables, therapist variables, client-therapist personality matching, and the “therapeutic alliance.” Further, Jennings and Skovholt cited evidence that the therapeutic alliance has consistently been shown to have the most significant impact on successful client outcomes, a hypothesis which has been supported consistently since then (Norcross, 2010). Jennings and Skovholt concluded, “Assuming that the personal characteristics of the therapist influence the quality of the therapeutic alliance, it may be useful to understand more fully the qualities effective therapists bring to their work. Even more helpful would be to identify the characteristics of master therapist, those considered the ‘best of the best’ among mental health practitioners” (Jennings & Skovholt, 1999, p. 3).

Self-reflection also plays a role via constant consideration about one’s clinical knowledge in clinical reasoning and decision making (Shepard et al., 1992; Zahm, 2009).

“Expertise” equals more than “experience”. *Experience* and *expertise* are distinctly different constructs (Benner et al., 1992; Jennings et al., 2003), as are *competence* and *expertise* (Overholser, 2009). Thus, although professional development may lead to expertise or master status, this is not necessarily the case. “Through persistent effort and dedication of professional development, competence may evolve into expertise” (Overholser, 2009, p. 133), expertise implies superior skills, beyond the level expected of the average professional (Overholser, 2009). “Expert practitioners are thought to ‘do something better,’ because they know how to do the ‘right thing at the right time,’ and thereby ‘provide better care’” (Resnick & Jensen, 2003, p. 1090).

Skovholt et al., (1997) argued, "Our own view is that expertise occurs when the practitioner has evolved to an internalized style after thousands of hours of practice and an average of 15 years of professional experience. At this point the practitioner has internalized theory and research, found a comfortable working style, development a method of judging success, and shed elements of the professional role which are incongruent with the self" (p. 364). Although, there is debate about the length of time necessary to become an expert in the helping professions, most contend it takes a fair amount of time, perhaps a decade or more (e.g., Ericsson & Smith, 1997, Fook et al., 2000). However, length of experience does not necessarily indicate expertise (Fook, 2000). Thus, although experience is essential for expertise, experience alone does not necessarily produce expert practitioners. These sentiments are echoed by investigators in other fields.

Extrapolating from these other fields, one could postulate that cognitive strategies and clinical experience are a necessary part of mastery or expertise in genetic counseling, but alone do not equate with expertise. Since expertise requires dimensions beyond those developed though experience and lengthy practice (Fook et al., 2000), one could potentially become an expert practitioner without having had extensive and lengthy experience (Fook et al., 2000). Furthermore, progress is not necessarily linear (Fook et al., 2000), but likely requires constant striving to improve one's work and clinical skills (Skovholt & Jennings, 2004). Expertise may, in fact, describe *a type of practice* rather than a level of achievement (Fook et al., 2000).

The difficulty generating an adequate operational definition of expertise, has, in fact, prompted some authors to discount the concept altogether within a discipline that is

multifaceted as opposed to focused on one single domain. (cf. Lichtenberg, 1997). This argument bears some consideration in its application to genetic counseling, which is, indeed, multifaceted. Lichtenberg (1997) contends that the salient aspects of counseling are clinical judgment and decision-making, and that these "domains" are more relevant than overall expertness in a multifaceted field. While there is some merit to this point, a strictly cognitive interpretation of what it means to truly excel, likely ignores important variables (Hubble et al., 2010).

Indeed, Fook et al.'s (2000) model of professional development in social work differentiates between experienced and expert practice. They note a distinction between experience and expert as one in which experts' practice is innovative or creative, and involves openness to new ideas and the ability to frame problems in complex non-routine ways. "Experts may tend to define tasks in way which required them to work at the edge of their competence rather than in routines ways" (Fook et al., 2000, p. 180). These investigators term this differentiating difference as "creativity and artistry" (p. 180). Their model, too, indicates elements of master practitioners extend beyond cognition and experience.

Studies of Expertise in Related Fields

Other medical and counseling fields have explored exemplary or expert practitioner development. Findings regarding this phenomenon have often emerged from more broad-based studies of professional development in general. The results have informed the generation of discipline-specific models of professional development. This section considers characteristics of pinnacle development in the fields of nursing, social work, physical therapy and counseling/psychotherapy. These fields were selected for

review because of their commonalities with genetic counseling by virtue of being medical professions and/or by involving counseling and/or information provision. Additionally, the research reviewed next represents initial and systematic investigation into what it means to be an expert practitioner in each particular discipline. Included in this review are theoretical and empirical articles on models of professional development, comprehensive reviews of the professional literature by individuals in those fields, and research specifically focused on developing mastery or expertise.

Included are reviews of investigations that are the first in each particular field, and most of those studies involved qualitative methods. "Expert" participants for the studies reviewed were selected in various ways, sometimes on the basis of years of experience alone, sometimes based on experience and some type of nomination by peers, supervisors, or other experts. Participants deemed "experts" in these studies had experience ranging from 5 years to 20 years. Some studies included a large number of participants (e.g., 100), while others involved groups of as few as 3 participants each. Individual interviews comprise the most common method of data collection, while some studies involved group interviews as well. Some of the studies included observation of the experts doing their work, with some videotaping experts at work and later interviewing them to obtain their reflections on their videotaped performance.

Characteristics of expert nurses. Investigators have begun to define the characteristic of "expert nurses" (Adams et al., 1997, p. 217), or what Benner (2000a) terms, "the wisdom of nursing" (p.99). Studies of expert nurses began in the early 1980s and proliferated in the 1990s (Adams et al., 1997). Although many authors use the term "expert" or "expert nurse," others use the word "specialist" or "advanced practitioner"

(Adams et al., 1997). Within nursing, there seems to be some consensus on the use of the term "expert nurse," drawing on a definition postulated by Benner (1984). Benner and colleagues' (1984, 2009) model is frequently cited in articles on professional development in the nursing literature.

Beginning in 1987, Benner invited nurses to submit personal accounts of clinical excellence to the American Journal of Nursing for a series called "Dialogue With Excellence" (Benner, 1987, p. 1170). She encouraged critical incident type narratives by asking for stories of clinical situations they reflected on many times, and co-authored a series of more than a dozen vignettes published over the next year.

Later, Benner and colleagues conducted a series of studies involving expert practice in critical care nursing based on the Dreyfus Model of Skill Acquisition (Dreyfus & Dreyfus, 1986). Benner, Tanner and Chesla (1992) investigated the nature of skill acquisition and practical knowledge exhibited in expert nursing practice through interviews and observation. Their participants were 105 nurses at 8 hospitals in three locations who worked in ICU units caring for newborns, children and adults. The investigators divided participants into three groups based on years of experience and nomination by their peers or supervisor. Members of the expert group had at least five years of experience and were "recognized by peers and supervisors as expert practitioners" (Benner et al., 1992, p. 15). The investigators conducted group interviews in which participants were encouraged to give narrative accounts of their clinical practice by describing specific patient-care situations. Forty eight of the participants were also interviewed individually about their work and observed during practice at least three times; however the authors do not differentiate how many of these were in the "expert"

group. The research team used qualitative analytical methods to identify themes and practices characteristic of each level of practice.

The authors concluded that "the expert's perception of the clinical world is vastly different from that of the beginner or competent and more fully developed than the proficient level." (Benner et al., 1992 p. 25). The expert nurse is distinguished by drawing on experience, using intuition, and incorporating a comprehensive view of the situation. They found that expert nurses were able to grasp situations immediately and attend to salient information, while less relevant information stayed in the background. Benner et al. (1992) also concluded that expert nurses knew when they had a good grasp of a situation and were uncomfortable when they did not. They were open to the situations they found themselves in, were able to recognize patterns, and were able to coach other professionals to see the situation in the same way they did. These expert nurses also seemed able to manage the complexity of their work both clinically and psychosocially. For example, Benner et al. (1992) concluded they were able to manage rapidly changing situations while attending to many aspects of the case simultaneously, including addressing patients and family concerns and needs. Based on this study and an earlier one of 51 experienced nurse clinicians, 11 new graduate nurses and 5 senior nursing students (Benner, 1982), Benner et al. (1992) concluded that expert nurses had an "intuitive grasp on a situation" (p. 405) and that their findings fit within the Dreyfus Model.

Since Benner's (1984) ground-breaking study, two authors have conducted thorough reviews of the growing literature on expertise in nursing. In a 1997 review of more than 20 articles (Adams et al., 1997) concluded that Benner's work shows that

nurses progress through a sequence of skill acquisition to reach a level of expert practice. Expert nurses are characterized by their intuition, skills and competencies, and their professional roles (Adams et al., 1997). For example, Adams et al. (1997) note that experts in nursing are able to discriminate between the essential components of a problem and related wider issues. They have a strong grasp of clinical skills, and also an intuitiveness which is based on deep knowledge and experience, and which leads to insight and action without the use of conscious reasoning. Adams et al. (1997) conclude that the expert nurse is distinguished by intuition, superior skills and competencies, specific role functions, and clinical outcomes. Further, these authors' conclusions are consistent with Dreyfus and Dreyfus's (1996) contention that expertise is gained through practice.

According to Adams et al.'s (1997) review of the nursing literatures, expert nurse skills include creative problem-solving and decision-making, selective assessment techniques to evaluate situations and generate alternative actions, and superior planning abilities. They are skilled in planning for and in adapting to complex and continually changing situations, and they are able to recognize the patterns and relationships within clinical care. Expert nurses are also collaborative, good at negotiating, and responding to patient and family needs. Their excellent relationship skills also extend to colleagues and others in the medical environment. These characteristics seem to highlight cognitive abilities, relational skills, and "calm under fire".

More recently, Morrison and Symes (2011) conducted an integrative review summarizing research on the characteristics of expert nursing practice conducted since Adams et al.'s (1997) review. They considered research on the characteristics of expert

nursing practice across specialties, settings, and counties. They examined a total of 16 studies, of which five were non-experimental quantitative studies, and 11 were qualitative studies. They found characteristics of expert practice included: knowing the patient; intuitive knowledge, including pattern recognition; reflective practice; risk taking; and skilled know-how. These writers conclude that nurses gain expert practice though experience in specialized practice settings, reflections on their experiences, and meaningful relationships with patients, families and colleagues.

They further note that, "grounding the themes was nurses' emotional involvement with patients" (p. Morrison & Symes, 2011, p. 164), a finding reported in 14 of the 16 studies they reviewed. Knowing the Patients was a central finding in four studies they reviewed. Morrison and Symes conclude that knowing a patient's wider context allows nurses to recognize the salience of important aspects of a particular patient's situation and to use those cues to guide their actions and judgments – behaviors the authors regard as particularly relevant within psychosocial realms.

Reflective Practice allows for learning from mistakes, while Risk-Taking allows for advocating for patients based on subtle cues and confidence to report those cues to physicians. Also contributing to development of nursing practice expertise are Work Environmental Factors, including nursing leadership, autonomy, positive nurse-physician relationship, nurse-patient relationship, role model mentors, and recognition.

Characteristics of expert physical therapists. In the field of physical therapy, colleagues Shepard, Hack, Gwyer and Jensen (Jensen et al., 2000; Resnick & Jensen, 2003; Shepard et al., 1999) conducted a series of studies of the clinical practice of novice, experienced, and expert physical therapists. Their work shaped the current understanding

for expertise in that field. They first conducted studies on differences between novice and experienced physical therapy practitioners and then investigated attributes of master and novice physical therapists (Resnick & Jensen, 2003). Similar to the work on professional development in other fields, they developed a conceptual framework for expertise in their field based on the Dreyfus and Dreyfus (1976) model, but also informed by studies of expertise in teaching (Livingston & Borko, 1989). Unlike researchers in other fields, they also used a number of different investigative methods, including videotaping, observation, and interviews. This group of researchers seems to be the only one to also include patients' perspective or data in their research methods. Specifically, participants in their expert (and other) groups were selected from a large data base containing patients' health-related quality of life outcome measures. The investigators used these patients' outcome measures to aggregate patient outcomes for each therapists participating in the data base. The therapists whose patients had the highest means scores were included as potential participants in the expert group. Thus, the expert group was,
by definition, based on outcome measures of patients' health-related quality of life.

As is true in genetic counseling, these researchers noted that understanding expertise is important due to the increasing complexity of their field, pressure from the health care systems for effective and efficient patient management, and the need for quick patient diagnosis, intervention and education (Jensen et al., 2000). Understanding expert practitioners' views of their role in health care, how they gather, sort and apply information, and knowing the beliefs guiding their patient interactions are beneficial to their discipline (Jensen et al., 2000).

These researchers investigated practice differences between novice and expert clinicians and how these differences develop. They defined "novices" as those with less than 2 years experience, and "experts" as those with 12 or more years of experience. In a 1999 study, they videotaped 9 physical therapists, and noted the differences between novice and experts physical therapists concern "how they worked with patients, how they elicited and used information, and how they managed the chaos of the clinical setting" (Shepard et al., 1999, p. 749).

In their next study (Jensen et al., 1992), the researchers added "clinical competence" to their definition of expertise. Akin to studies of master therapists (Jennings & Skovholt, 1999) and to some degree studies of expert nurses (Benner et al., 1992), for this study, their 3 novice and 3 expert physical therapist participants were nominated by a panel of their clinical peers, and the researchers began exploring what they termed "attribute dimensions." This study included nonparticipant observation, patient interviews, interviews with clinicians regarding perceptions of their decision-making and clinical skills, and review of patient records. The researchers found, compared to the novices, master clinicians had more extensive knowledge, individualized their evaluation and teaching for each patient, were more responsive in their interactions, and used more encouragement and tactile cues in their interventions. In support of the Dreyfus Model, Jensen et al. (1992) found that expert physical therapists were better able to identify what was salient in their environment, and they were less routine and standardized and more patient-specific. Experts were comfortable, confident and more elaborate in their knowledge than were novices. They also found that expert physical therapists focused on connecting with their patients, and they were more "patient-

centered" than technique-centered. The authors' quotes from expert practitioners indicate a more holistic view of the patient which includes their life contexts.

These investigators also studied clinicians across specialty areas (Jensen, Gwyer, & Shepard, 2000), an issue that may be of concern in identifying expert genetic counselors who also work in a number of specialties which may require different sets of skills for optimum performance. The goal of this investigation was to capture the way therapists routinely think about and engage in patient care. Their participants were 12 expert physical therapists nominated by leaders of the field's national professional association, which the authors contended was a peer nomination process. Participants had 10 to 31 years of practice experience, all were actively involved in teaching, and most were involved in their national professional association. Thus, for this study, the definition of expertise extended beyond clinical work, to include teaching and professional advocacy.

The researchers used a multiple case study design in which each of 4 investigators collected data on three expert participants within a single clinical area. Data collection was via observation, videotaping of three sessions for each participant, semi-structured review of videotapes with participants, review of documents such as participants' published papers, and analysis of structured tasks. Videotaped treatment sessions were used as a stimulus for the expert therapist interviews. Data were analyzed through the development of 12 comprehensive case reports and 4 composite case studies, one for each specialty area. Each case report contained six components (e.g., type of knowledge used, description of clinical reasoning process, expert philosophy, expert's disposition, personal values and beliefs). Themes were generated via grounded theory from the case

study reports, resulting in a theoretical model of expert practice in physical therapy. The investigators found that expert practice included four dimensions. One dimension relates specifically to movement assessment, which is not of concern in this literature review. The remaining three, however, may be relevant: “(1) a dynamic, multidimensional knowledge base that is patient-centered and evolves through therapist reflection, (2) a clinical reasoning process that is embedded in a collaborative, problem-solving venture with the patient… and (4) consistent virtues seen in caring and commitment to patients” (Jensen et al., 2000, p. 28).

The investigators noted that the multi-dimensional knowledge base included a deep understanding of their specialty area, ability to compare knowledge across patients with similar concerns, and skills in finding resources (Jensen et al., 2000). They also noted their expert participants were highly motivated to continue learning and had had mentors who stimulated their thinking. Patients were considered a powerful source of knowledge, and these practitioners welcomed challenging cases (Jensen et al., 2000).

Jensen et al. (2000) also reported that the experts focused on the patient as a person and worked collaboratively and innovatively. They found these expert practitioners were patient-centered and focused the patient interview on allowing the patient tell their story, rather than on therapist-generated questions. While addressing presenting concerns, the experts also sought to understand the patient beyond their presenting problem, such as understanding their support system, home and work contexts. The authors noted these practitioners worked hard to understand what the patient needed to be successful, viewed their patients as the experts on information about themselves, and believed empathic listening and observation would tell them what they needed to

know about their patients. Thus, patients were intimately involved in the process, and shared in problem-solving and in decision-making. Thus, it seems that, as in genetic counseling, client-centeredness and the patient-clinician relationship is important, as is a collaborative and equal working relationship (McCarthy Veach, et al., 2007). These factors are also reflected within the investigators' theme of Virtues of Caring and Commitment, which they acknowledge as contributing to a trustworthy relationship (Jensen et al., 2000).

Jensen et al. (2000) further found that these expert clinicians set high standards for themselves and had a strong inner drive to succeed and continue to learn. They were driven to stay current in their specialties and felt intellectually challenged and continually intrigued by their patients and by solving their patients' problems. They reported finding common personal philosophies across the experts, such as a belief that people should be healthy and involved in taking responsibility for their own health. Further, they found these clinicians felt responsibility to use their knowledge and skills to benefit their patients but were also reluctant to impose their own judgments. They exhibited modesty and confidence in what they knew and in what they did not know. .

Jensen et al. (2000) concluded, "Practice begins and ends with patients" (p. 34), while Shepard, et al. (1999) stated, "it is difficult, if not impossible, to extricate [expert therapists'] philosophies of practice from their knowledge or their knowledge from their clinical reasoning, (Shepard, et al., 1999, p. 756). This description seems quite similar to Skovholt et al.'s (1997) idea of expert practitioners having evolved an internalized style of working that combines a comfortable working style with internalized knowledge and professional experience.

Characteristics of expert social workers. As in nursing and in physical therapy, Fook and colleagues (Fook, Ryan, & Hawkins, 1997a; 1997b; 2000) conducted a series of studies on professional development of social workers and created a theory of development based on the findings. They contend their theory of development pertains to many professionals who deal with complexities and uncertainties in their work. Their theory has received some cross-national validation (Ryan, Dowden, Healy, & Renouf, 2005; Ryan, Healy, & Renouf, 2004) and professional application (McCracken & Marsh, 2008; Nilsson, Ryan, & Miller, 2007) albeit only within social work.

Similar to Benner et al.'s (1992) work in nursing and Jensen et al.'s (2000) work in physical therapy, Fook et al. (1997a; 1997b; 2000) based their studies and their theory of professional development of social workers on the Dreyfus and Dreyfus (1986) model. Fook et al.'s (2000) "theory of expertise for working in uncertainty" (p. 181) included seven stages--Pre-student, Beginner, Advanced Beginner, Competent, Proficient, Experienced and Expert. In a five-year longitudinal study (Fook et al.'s (1997a; 1997b; 2000) they investigated levels of development via themes, critical incidents, context-free and situational rules used in practice, values (in terms of the practitioners' beliefs), skills (what they are confident doing), and "contextually/reflexivity (how responsible and involved they feel in a situation).

One study (Fook et al., 1997a) focused on 30 experienced social work practitioners who had been nominated as being expert practitioners by the field education staff of three Australian schools of social work. For this study the researchers defined "expert" as having at least five years of post graduate school work experience and having supervised at least five students on placement. The criteria were not rigidly applied,

however, and participants who did not necessarily meet them were also included, although the authors provided no additional information on this deviation.

The sample included 23 women and seven men, with a median age range of 40-49 years; one participant was under 30, and another was over 50. The median number of years since graduation was 15-19, although four had less than five years, and six had 25 years of experience. In semi-structured interviews, participants were asked to respond to practice vignettes as well as discuss their own critical incidents. Data were analyzed inductively and deductively. Themes were derived via content analysis using open coding, and data were also examined in relation to the Dreyfus and Dreyfus (1986) model of skill development.

Relevant to the present paper, Fook et al. (1997a) found that expert social workers focused on the complexities of their work (e.g., being simultaneously aware of the client as well as the client's life contexts, including possible conflicting ethics, values and interest groups). Expert social workers could prioritize tasks and goals while being "acutely aware of organizational and bureaucratic boundaries of their roles" (p. 406). They were confident in their interventions, in their sense of themselves as practitioners, and in their professional identity. Further, these expert participants were clear about what action to take, and they were confident in their capacity to influence the situation. Thus, they seemed to embrace a sense of self-efficacy about their work.

Fook et al. (1997b) also compared the responses of this group of experts to a group of beginning students from a previous study (Ryan, Fook, & Hawkins, 1995). Compared to the beginners, expert social work practitioners were more likely to take situational factors into account in their assessment and intervention, their interventions

were more specific, and they were based on previous experience and on a theoretical framework. Expert practitioners had a greater sense of other outside resources and how they might be used, and they were more comfortable in dealing with those they perceived to be less powerful. Compared to the beginners, expert practitioners had integrated their personal and professional identities and held a more positive view of their profession. These results reflect the internalized style found in other fields (e.g., Jensen et al., 2000; Skovholt et al., 1997).

The researchers concluded that expert social workers appear to be more holistic, take a broader view of their clients (systemic vs. individualistic), and they are better able to deal with complexities. Particularly, expert social workers may have awareness of and ability to deal with complex situations, often involving competing factors. A particular strength of this study is their comparison of experts with individuals at other levels of development, which allowed drawing distinctions based on developmental level.

Overall, Fook et al. (1997b; 2000) concluded that expert practitioners are characterized by their ability to deal with complexities and uncertainties in changing situations. Within social work, experts make values- and knowledge-based decisions and actions in contexts that are multi-leveled and may include conflicts of interest (Fook et al., 1997b, 2000). Experts show flexibility and creativity. As they are unable to predict situations which may arise, Fook et al. (2000) proposed that experts approach situations with a "particular *process*" rather than "an expected outcome" (p. 187). In this way they engage with the situation as opposed to an end result. This process involves identifying the multi-faceted aspects of the situation and considering a range of options.

While the process they describe includes some aspects particular to social work that may not apply to genetic counseling, several aspects of the process seem particularly applicable (e.g., engaging with multiple viewpoints and players). Expertise also involves flexibility; ability to tolerate ambiguity, anxiety, disorder and conflict, and accept ambivalence and paradox, integrate knowledge and theory, and engaging in self-reflection; and ability to prioritize and quickly determine crucial factors and strategies needed at any one time. Experts may also view change as an opportunity, and they are able to work with a whole person, group or organization. They are able to see the bigger picture, and perceive their profession as a calling.

Fook et al. (2000) identified 11 general dimensions of expertise: Substantive Knowledge such as facts or theories; Procedural Knowledge, such as translating substantive knowledge into practice; Skills, such as identifying and applying helping skills; Values, including identifying ideals and beliefs; Contextuality, or the extent to which practitioners are "context-bound" and their awareness of their place in the context; Reflexivity, degree of practice within a context and the degree of feeling empowered to act; the Breadth of Vision of service as extending beyond their current job; Flexibility, the ability to generate a range of options; Use of Theory; Approach, or the lens they apply to their work; and Perspectives on Profession, including development of professional identity (Nilson, Ryan & Miller, 2007).

In a cross-national study, Ryan, Merighi, Healy, and Renouf (2004) investigated the characteristics of expertise in mental health social workers in the United States and in Australia using group interviews that included asking participants to describe a memorable practice situation. Thirty five participants were peer nominated; however, the

authors noted they made the final decision on whether they considered the participants to be experts, based on Fook et al.'s (2000) framework of expertise. These selection procedures resulted in only 19 participants in the study. Participants had practiced from 8 to 25 years, and the sample included 7 Asian/Pacific Islander and Hispanic Latino practitioners. The investigators reported results indicating the expert social workers were confident in their knowledge, skills, and roles; they were optimistic and held a sense of hope for their clients' improvement; and that they authentically cared for their clients. The authors noted the resemblance of their findings to Bandura's (1997) high self-efficacy expectations. They also noted their findings were consistent with Benner et al.'s (1996) importance of caring in expert nursing. Unfortunately the researchers did not discuss any cross national similarities or differences, or any results that might reflect on the diversity of their sample. Most likely, the small sample size precluded detection of thematic differences based on those characteristics.

In two follow-up studies Ryan and colleagues (Ryan et al., 2005; Ryan et al., 2004) added observational, interview, and focus group methods to their design. The results of the observation study are particularly interesting. In that study Ryan et al. (2005) observed 6 peer-nominated expert social workers in Australia during their work day in community mental health settings and interviewed them via a semi-structured interview afterwards regarding their understanding, interpretations, and meanings of events. Qualitative data analysis yielded eight themes, which seem particularly applicable to genetic counseling work.

Four themes included: Knowledge that permeated the social workers practice; "A Lot of Hard Grind" (p. 287), including "hard work and [its] frequently challenging

nature" (p.287) and also included working with difficult clients; "We are Here For the Clients," (p. 287) which expressed the experts' passionate commitment to their clients' well-being and empowerment, as well as a strong client focus; "The Complicated and the Difficult", (p. 287) which included working with layers of complexity, and multiple problems within a given interaction, as well as taking multiple viewpoints simultaneously.

Within their theme of The Complicated and the Difficult", (p. 287), Ryan et al. (2005) stressed the clinician's need to "hold simultaneous viewpoints of a situation and the number of levels of focus" (p. 288), such as the client's current mental and physical health, current levels of risk, legal rights, and family relationships. The authors commented that the handling of complex situation was often "striking" and "masterly" (p.288), as the experts addressed multiple issues and multiple layers of complexity in a given interaction. Likely many genetic counselors can identify with this complexity (Miranda, 2007).

Their sample of expert clinicians found particular pride when successfully working within the complexity (Ryan et al., 2005). Successful communication as well as resolving clients' concerns were often reported as the most satisfying aspect of the work and a point of personal inspiration for the clinicians (Ryan et al., 2005).

Perhaps due to the complexity of the work, two additional themes including the importance of supervision, including positive feedback and encouragement; and the emotional aspects of their work, including being under stress in anticipation of a difficult situation (Ryan et al., 2005).

And lastly, two themes related to working within the field of social work. “The Stone in the Shoe” (p. 287), refers to the slow process of long-term gradual change within families, teams and work settings, and includes a components of sometimes feeling undervalued. “Going Ten Rounds with the System” (p. 287) related to the struggle of gaining professional credibility, autonomy, recognition and respect within a hierarchical system.

In 2008, McCracken and Marsh connected expertise in social work with evidenced-based practice and clinical decision-making, both of which they contend require “reflection and critical thinking” (p. 301). They define practitioner expertise as a set of “cognitive tools that aid in the interpretation and application of evidence” (p. 302) and includes three overlapping knowledge and skills sets which develop with experience. The skill sets are clinical, technical and organizational. Clinical skills include direct practice skills (knowledge, assessment, engagement, relationship, and skills related to communicating empathy, warmth, and genuineness). Technical skills included formulating questions, information search, and evaluating the validity and reliability of the findings. Organizational skills related to teamwork, organizational design and development, and leaderships.

Characteristics of master psychotherapists. Two teams of researchers have conducted landmark studies of professional development in the field of psychotherapy, Skovholt and colleagues (e.g., Skovholt & Ronnestad 1991; Ronnestad & Skovholt, 2003), and Orlinsky and colleagues (e.g., Orlinsky & Ronnestad, 2005).

In a seminal series of studies begun in the 1990s, Skovholt, Ronnestad, Jennings and colleagues investigated expertise in therapy and counseling. They sought to describe

the "master therapist," a recurring concept with respect to expertise within the counseling professions (Jennings & Skovholt, 1999; Skovholt & Jennings, 2004). In 1999, Jennings and Skovholt used purposeful sampling methods (peer nominations and "snowball" recruiting) to identify a sample of 10 psychotherapists considered to be "seasoned, well-regarded" therapists (p. 8) by their professional peers in an upper Midwestern metropolitan area. They asked "well-regarded practicing psychologists" (Jennings & Skovholt, 1999, p, 8) to nominate "master therapists" based on three criteria: a) the person is "considered a master therapist, b) the person is frequently thought of when referring a friend of relative because the therapist is "considered to be the 'best of the best" (p. 4), and c) the nominator would be confident in seeing this person for their own therapy. They obtained 103 nominees, and invited those who received four nominations to participate. All of the participants were in private practice at the time. They ranged in age from 50-72, with experience ranging from 21 to 41 years.

Using an interview-follow-up design, the investigators conducted in-depth, semi-structured interviews with each participant, about their personal characteristics, career growth, perceptions of expertise and their own expertise

Responses to the interviews were analyzed qualitatively, and resulted in a number of cognitive, emotional and relational domains (Jennings & Skovholt, 1999). A follow-up interview was conducted with each participant to evaluate the accuracy of the themes, resulting in 8 supported themes. The results indicated that master therapists are voracious learners; they seek continuous professional development; they are curious and have a love of learning. Furthermore, they draw on accumulated life and work experience, and these experiences seemed to have added depth and competence to them

as people and professionals. However, the interviewees noted that "experience alone did not guarantee optimal development" (p. 6), and that "commitment and openness to learning from one's experience" was essential (p.6). Also, these master therapists did not merely tolerate cognitive complexity and ambiguity, they sought it out.

Jennings and Skovholt (1999) also found the master therapists they interviewed were emotionally receptive. For example, they were "self-aware, reflective, nondefensive and open to feedback," and they were "eager to learn more about themselves and their work," (p. 7). Further, master therapist seemed to be mentally healthy and attended to their own emotional well-being. For example, they sought to be "congruent, authentic and honest" (p. 7) in both in their personal and professional lives, they were comfortable with themselves, and they "seemed to have struck a healthy balance between confidence and humility" (p. 7). They were also aware of the impact of their own emotional health on their work. The investigators reported that master therapists possessed strong relational skills, sometimes developed through their own emotional wounds. Words the authors (Jennings & Skovholt, 1999) used to describe the participants included caring, respectful, and having a genuine interest in people. In line with their strong relational skills, Jennings and Skovholt found that master therapists held strong beliefs that the "foundation for therapeutic change is a strong working alliance" (p. 8). They viewed therapy as a partnership, held a belief in clients' ability to change, and had respect for their clients' self-determination. Master therapist sought to create safety and support for their clients, but balanced with challenging them and being with them during intense moments (p. 8). Additionally they were skilled at the "art of timing, pacing and 'dosage'" (p. 8) of their interventions.

Jennings and Skovholt (1999) concluded that becoming a master therapist is more than an accumulation of time and experience. They further concluded their results converge with previous findings regarding competence and expertise, and with those specifically concerning therapist professional development. They theorized that expertise in psychotherapy extends beyond the cognitive domain (Skovholt, Ronnestad, & Jennings, 1997) to also require emotional and relational dimensions.

Several follow up studies have explored the master therapists' construction of the therapeutic relationship (Sullivan, Skovholt, & Jennings, 2005), developmental factors (Jennings et al., 2005) and ethical values (Jennings, Sovereign, Bottorff, Mussell, Vye, 2005). In a culminating discussion of their research, the "Portrait of the Master Therapist: Exploring Expertise in Therapy and Counseling," Skovholt and Jennings (2004) identify 18 central characteristics of master therapists as identified in Table 1. Jennings and colleagues (Jennings et al., 2008) found similar overlap in the findings of their qualitative study of expertise in 9 peer-nominated expert psychotherapists in Singapore. They investigated personal characteristics, developmental influences, and therapy practices. Personal characteristics included being empathic, nonjudgmental, and respectful. Developmental influences included experience, self-awareness, humility, and self-doubt. Additionally, this investigation identified the centrality of the therapeutic alliance and an empowerment/strength-based approach in its participants. Areas of professional growth included professional development practices, and the benefits of teaching or training others. As with the previous studies by Skovholt and colleagues, however, this investigation included no comparison group. The findings, however, do

provided some evidence of cross-cultural consistency in characteristics of master psychotherapists.

Table 1 Characteristics of Master Therapists

Cognitive	Master therapists are voracious learners Master therapists use their accumulated life and work experience. Master therapists value cognitive complexity and the ambiguity of the human condition
Emotional	Master therapists are emotionally receptive—they are self-aware, reflective, non-defensive, and open to feedback Master therapists seem to be mentally healthy and mature and attend to their own emotional well-being Master therapists are aware of how their emotional health affects their work
Relational	Master therapists have strong relational skills Master therapists' beliefs about human nature help build strong working alliances Master therapists are expert at using their exceptional relational skills in their work

*Source: Jennings & Skovholt (1999), p. 33-46.

In possibly the largest study of therapist professional development to date, and a landmark body of work, Orlinsky, Ronnestad and colleagues (2005) collected data from nearly 5,000 psychotherapists internationally in a 15-year study of psychotherapists at all careers levels. As a project of the Society for Psychotherapy Research's Collaborative Research Network, the project considered positive and negative factors contributing to

development of psychotherapists (Orlinsky & Ronnestad, 2005). As in the present study, these researchers asked therapists about their work, stresses and satisfactions, skills, goals, difficulties and coping, and what are they like as people. This research stands out among the others described previously in its sample size, thoroughness, comparison of cohorts across developmental levels, and methods, which unlike the studies in the other fields discussed, included quantitative methods.

In part of a large on-going study of professional development of psychotherapists, these researchers (Orlinsky & Ronnestad, 2005) compared cohorts based on developmental level. Post graduate levels of development included Established (7-15 years of experience, mean age = 43), with more than 1,400 in the group; Seasoned (15-25 years, mean age = 49) with more than 1,000 in the group; and Senior (25 to 55 years, mean age = 61). The senior group included 400 clinicians who averaged more than 31 years in practice.

Orlinsky and Ronnestad (2005) view cumulative career development as culminating in a high level of therapeutic proficiency in technical clinical skills/expertise as well as in relationship skills. They postulate that these skills "…include mastery of techniques and strategies, moment-by-moment understanding of process and the ability to deal effectively with the subtle psychological and emotional undercurrents of involvement between patient and therapist" (Orlinsky & Ronnestad, 2005, p. 112).

Based on responses to a series of self-report measures, Orlinsky and Ronnestad (2005) found that fewer than 47% of their total sample felt they had achieved "mastery," defined as "precision, subtlety and finesse" (p. 113) in their therapeutic work. Direct measures of mastery were closely related to time in practice. Almost all of the 400

"senior therapists" (78%) perceived themselves as having achieved a high level of mastery, compared to only 16% of novice therapists who viewed themselves as having achieved a high level of proficiency. (Although 72% of the novices did think they had achieved moderate mastery).

These researchers (Orlinsky & Ronnestad, 2005) found significant differences across successive cohorts in mean levels of technical expertise and in basic and advanced relational skills. They also found declining levels of professional self-doubt across cohorts. When confronted with difficulties in practice, Senior and Seasoned therapists were more often inclined to problem solve with patients and to exercise reflective control, a coping strategy relating to feeling positively involved with their work (Orlinsky & Ronnestad, 2005). As the name suggests, reflective control (Orlinsky, et al., 2005) involves "reviewing privately how a problem has arisen trying to view the problem from a different perspective, attempting to contain one's own troublesome feelings, interpreting the patient's resistant or troublesome behavior, and setting limits to maintain an appropriate therapeutic frame" (p.52).

Therapists at all career levels experienced themselves as highly invested in relating to patients, but this level of investment was highest of all among senior therapists. Further, the authors noted, "A shift in priorities appears to take place among senior therapists" (p. 156) and more than ever they attribute their professional growth to direct clinical experience. Another prevalent influence for senior therapists was experiences in their personal life outside of therapy.

Orlinsky and colleagues' (2005) research culminated in a theory of professional development emphasizing the importance of therapists' sense of "healing involvement."

That is, they “experience themselves as personally committed and affirming in relating to patients, engaging at a high level of basic empathic and communication skills, conscious of ‘Flow’ type feelings during session, having a sense of efficacy in general and dealing constructively with difficulty encountered if problems in treatment arose” (p. 164). Healing Involvement was found to be highest among Senior Therapists, and it leads to a greater sense of assurance, resourcefulness and flexibility in one’s work with patients. In turn, when therapist experienced these positive feelings about their work, they became more committed to it (Orlinsky & Ronnestad, 2005).

Summary of Professional Development in Related Fields

In summary, the concepts of professional development in general, and exemplary professional development in particular, have been the topic of previous research in many fields which have some overlap with genetic counseling. These include other medical fields which involve explaining medical issues to patients, such as nursing and physical therapy, and counseling-oriented fields, such as psychotherapy and social work. In each of these fields researchers have developed models of professional development, most basing their particular theories on the general development model of Dreyfus and Dreyfus (1986).

Each of these fields has also considered what it means to be a “best of the best” practitioner within their particular discipline. The term used to describe these highly respected professionals varies across the disciplines, with some considering them “masters,” others preferring the term “expert,” and none defining either of these words in a particularly succinct and operational way. Thus, it seems there is such a concept, but what to call it is problematic and idiosyncratic, with inadequate operational definitions.

Methods used to study both professional development and master development across the fields have been primarily qualitative, with semi-structured interviews being the most prominent method. Some researchers have used observational methods in attempts to describe the practices of expert professionals. One research team conducted extensive research on psychotherapists utilizing quantitative methods, but they are the exceptions rather than the rule. By and large data are self-reported by the practitioner participants.

Participant selection for the studies of master or expert practitioners has also been quite variable. Some use length of experience as the only criterion, others use some sort of nominating criterion, including nomination by peers, teachers, and members of professional associations, and some include nomination based on specific role functions (e.g., having been a supervisor). Sometimes researchers acknowledge they did not strictly adhere to their own inclusion criteria. Some of the participants considered experts had less than five years experience, while others had more than 30 years experience in their respective fields. Some studies reported participants' ages, but not other demographic information (e.g., gender, ethnic group identification). Thus, the participants considered to be expert or master, vary widely, as do the number of participants per study, from 3 to about 400.

Some of the studies include comparisons across developmental stages within their field, while others do not. In the qualitative studies there is little evidence of triangulation.

Given the broad methodological differences across studies, it is difficult to draw definitive conclusions about master or expert practitioners in the helping professions, and indeed, that is beyond the scope of this review. Yet, there do seem to be some thematic

similarities among individuals considered to be experts in the four fields as shown in Table 2**.** Based on the literature reviewed thus far, it appears that master or expert practitioners in certain counseling and medical professions share: 1) a multidimensional knowledge base developed through life and work experience, 2) an ability to recognize patterns within their clinical encounters 3) a set of more elaborate cognitive skills than those professionals who are less developed, 4) and a strong motivation to continue learning. Additional themes that may be common among experts in these professions are openness, innovativeness, and creativity.

Generally, most of those practitioners considered to exemplify development are patient-centered and have a holistic view of their clients, a strong commitment to them, and an authentic interest in them. They seem to attend to their clients as multidimensional individuals and strive to understand and attend to them within the patients' life contexts; they also attend to their clients' psychosocial dimensions.

Table 2. Master Practitioners' Characteristics Reported in Studies in the Fields of Psychotherapy, Social Work, Nursing, and Physical Therapy

THEMES REPORTED IN FOUR FIELDS

Theme		Authors	Field
Holistic comprehension of complexity			
	Perceives, understands, and prioritize salient issues		
		Adams et al. (1997)	Nursing
		Benner et al (1992)	Nursing
		Fook, Ryan, & Hawkins (1997a)	Social Work

	Fook, Ryan, & Hawkins (1997b)	Social Work
	Jensen et al. (1992)	Physical Therapy
Grasp patterns	Adams et al. (1997)	Nursing
	Benner, Tanner, and Chesla (1992)	Nursing
	Jensen et al. (2000)	Physical Therapy
	Morrison and Symes (2011)	Nursing
	Skovholt and Jennings (2004)	Psychotherapy
	Ryan et al. (2005)	Social Work
Flexibility, creativity and/or easily adapts to complex and continually changing situations		
	Adams et al. (1997)	Nursing
	Benner et al (1992)	Nursing
	Fook, Ryan, & Hawkins (1997a)	Social Work
	Fook et al. (2000)	Social Work
	Jensen et al. (1992)	Physical Therapy
	Jensen et al. (2000)	Physical Therapy
	Jennings and Skovholt (1999)	Psychotherapy
	Orlinsky and Ronnestad (2005)	Psychotherapy
	Rønnestad and Skovholt (2003)	Psychotherapy
	Ryan et al. (2004a)	Social Work
	Ryan et al. (2005)	Social Work
	Shepard et al (1999)	Physical Therapy
Intuitive, internal, and/or personalized working style		
	Adams et al. (1997)	Nursing
	Benner et al (1992)	Nursing
	Fook et al. (2000)	Social Work
	Morrison and Symes (2011)	Nursing
	Jensen et al. (1992)	Physical Therapy
	Orlinsky and Ronnestad (2005)	Psychotherapy
	Rønnestad and Skovholt (2003)	Psychotherapy
	Skovholt and Jennings (2004)	Psychotherapy
	Skovholt, Ronnestad and Jennings (1997)	Psychotherapy
Confident in and/or trust own professional judgment		
	Benner et al (1992)	Nursing
	Fook et al. (1997a)	Social Work
	Fook et al. (2000)	Social Work

Theme		Authors	Field
		Jennings and Skovholt (1999)	Psychotherapy
		Jensen et al. (1992)	Physical Therapy
		Jensen et al. (2000)	Physical Therapy
		Orlinsky and Ronnestad (2005)	Psychotherapy
		Rønnestad and Skovholt (2003)	Psychotherapy
		Ryan et al. (2004a)	Social Work
		Skovholt and Jennings (2004)	Psychotherapy
		Skovholt et al. (1997)	Psychotherapy
Saliency of the relationship and/or patient/client-centered			
	Collaborative	Adams et al. (1997)	Nursing Fook et
		al. (2000)	Social Work
		Jennings and Skovholt (1999)	Psychotherapy
		Jennings et al. (2008)	Psychotherapy
		Jensen et al. (2000)	Physical Therapy
		Orlinsky and Ronnestad (2005)	Psychotherapy
		Ryan et al. (2004a)	Social Work
		Ryan et al. (2005)	Social Work
	Seeks to know the patient as a person and/or understand the context of their life		
		Fook et al. (1997a)	Social Work
		Fook et al. (1997b)	Social Work
		Jensen et al. (1992)	Physical Therapy
		Jensen et al. (2000)	Physical Therapy
		Jennings and Skovholt (1999)	Psychotherapy
		Morrison and Symes (2011)	Nursing
	Emotional connection and/or caring; committed to patient/client		
		Jennings and Skovholt (1999)	Psychotherapy
		Jensen et al. (2000)	Physical Therapy
		Orlinsky and Ronnestad (2005)	Psychotherapy
		Ryan et al. (2004a)	Social Work
		Ryan et al. (2005)	Social Work

THEMES REPORTED IN THREE FIELDS

Theme	**Authors**	**Field**

Extensive experience is necessary but not sufficient for expertise		
	Benner 1982	Nursing Fook,
	Ryan and Hawkins, (2000)	Social Work
	Jennings and Skovholt (1999)	Psychotherapy
	Morrison and Symes (2011)	Nursing
	Orlinsky and Ronnestad (2005)	Psychotherapy
	Skovholt and Jennings (2004b)	Psychotherapy
A deep knowledge base and understanding of their specialty area.		
	Jennings and Skovholt (1999)	Psychotherapy
	Jensen, Gwyer, and Shepard (2000)	Physical Therapy
	Jensen et al. (1992)	Physical Therapy
	Ryan, Healy and Renouf, N. (2004)	Social Work
	Shepard et al (1999)	Physical Therapy
Strong grasp of or superior clinical skills		
	Adams et al. (1997)	Nursing
	Morrison and Symes (2011)	Nursing
	Orlinsky and Ronnestad (2005)	Psychotherapy
	Resnick and Jensen, 2003	Physical Therapy
Possess excellent interpersonal skills		
	Adams et al. (1997)	Nursing Jennings
	and Skovholt (1999)	Psychotherapy
	Orlinsky and Ronnestad (2005)	Psychotherapy
	Shepard et al (1999)	Physical Therapy
	Skovholt and Jennings (2004)	Psychotherapy
Attend to or excellent process skills		
	Fook et al. (2000)	Social Work
	Jennings and Skovholt (1999)	Psychotherapy
	Orlinsky and Ronnestad (2005)	Psychotherapy
	Resnick and Jensen (2003)	Physical Therapy
	Shepard et al (1999)	Physical Therapy
	Skovholt and Jennings (2004)	Psychotherapy

Reflective practice		
	Jennings and Skovholt (1999)	Psychotherapy
	Jensen et al. (2000)	Physical Therapy
	Orlinsky and Ronnestad (2005)	Psychotherapy
	Morrison and Symes (2011)	Nursing
	Rønnestad and Skovholt (2003)	Psychotherapy
	Shepard et al (1999)	Physical Therapy
	Skovholt and Jennings (2004)	Psychotherapy
	Wainwright et al. (2010)	Physical Therapy
Mentoring, sense of generativity and/or leading		
	Benner, Tanner, and Chesla (1992)	Nursing
	Jensen et al. (2000)	Physical Therapy
	Ryan et al. (2005)	Social Work

THEMES REPORTED IN TWO FIELDS

Theme	**Authors**	**Field**
Self-aware and/or aware of own strengths and challenges		
	Benner et al (1992)	Nursing
	Jennings and Skovholt (1999)	Psychotherapy
	Jennings et al. (2008)	Psychotherapy
	Rønnestad and Skovholt (2003)	Psychotherapy
Attend to own emotional aspects of the work and/or able to "let go"		
	Rønnestad and Skovholt (2003)	Psychotherapy
	Ryan et al. (2005)	Social Work
Attuned to work setting dynamics		
	Fook et al. (1997a)	Social Work
	Morrison and Symes (2011)	Nursing
	Ryan et al. (2005)	Social Work
Commitment to professional growth or on-going learning		
	Jensen, Gwyer, and Shepard (2000)	Physical Therapy
	Rønnestad and Skovholt (2003)	Psychotherapy
	Skovholt and Jennings (2004)	Psychotherapy

Theme	Authors	Field
Learns from clients		
	Jensen et al. (2000)	Physical Therapy
	Orlinsky and Ronnestad (2005)	Psychotherapy
	Rønnestad and Skovholt (2003)	Psychotherapy

THEMES REPORTED IN ONE FIELD

Theme	Authors	Field
Personal life influences work		
	Jennings and Skovholt (1999)	Psychotherapy
	Rønnestad and Skovholt (2003)	Psychotherapy
Importance of healthy balance (competent but realistic; boundaries)		
	Rønnestad and Skovholt (2003)	Psychotherapy
	Skovholt and Jennings (2004)	Psychotherapy
Tolerate ambiguity	Jennings and Skovholt (1999)	Psychotherapy
	Rønnestad and Skovholt (2003)	Psychotherapy
Humbled to help	Rønnestad and Skovholt (2003)	Psychotherapy
Skilled at finding resources	Jensen et al. (2000)	Physical Therapy
Optimistic	Ryan et al. (2004a)	Social Work

Note. This table includes results from published studies or comprehensive literature reviews specifically focused on aspects of master practitioners in psychotherapy, social work, nursing and physical therapy. A full literature review of professional development in the four fields is beyond the scope of this paper. Therefore the list and endorsements should not be considered conclusive or comprehensive.

However, beyond that, and perhaps more importantly, the master practitioners in these studies seem to focus on connecting with their clients and creating meaningful relationships, perhaps indicating a centrality of the therapeutic relationship for expert practitioners. They may tend to take an empowerment or strengths-based view of their clients, they are reluctant to impose their own views on clients, but rather provide a sense of hope and nonjudgmental belief in their clients' success. They seem to be attuned to, understand, and easily work within multiple levels within the clinical situation, and they

possess a sense of emotional involvement (Skovholt & Ronnestad, 1997) or healing involvement (Orlinsky & Ronnestad, 2005) in their connection with clients. They also manifest depth and competence as professionals and as people (Skovholt & Jennings, 2004b) and are they have a confident and well-defined professional identity. They seem to be self-aware and self-reflective.

Models of Genetic Counselor Professional Development

Although not a model of development, per se, Abrams and Kessler (2002) offered a glimpse into the inner thoughts of genetic counselors at various stages of professional life through "quasi-fictional" (p. 6) narratives. The authors' reflected on genetic counselors' "understanding" of their professional lives…of the personal experiences, life histories, hopes, fantasies, knowledge, memories and judgments genetic counselors bring to their profession lives" (p. 5).

Rich with "doubts, angst, self-inquiry and inner struggles" (Abrams & Kessler, 2002, p. 6), the narratives are presented in a sequence that "approximates a developmental path many genetic counselors may follow in their careers" (p.6). The first two vignettes sequence from giving bad news and identifying with the family to one of ethical questions, personal motivations, gut-knowledge, and crashing internal conflict. Those are followed by an exploration of interprofessional relations, professional maturation and "differentiating from colleagues and mentors" in working style and responses (p. 6); to the important "contribution of the genetic counselor as a medical professional"…and "accommodation of various roles" (p. 6). And finally culminating into comfort in one's own skin personally and professionally, "a sense of balance developed over time" (p.14), self-reflection, a balance of vulnerability and assertiveness,

and a culmination in a sense of “purpose and fulfillment,” (p. 12) as well as acceptance of reality, purpose and direction—“a sense of completeness” (p. 15).

One study has taken a systematic, in-depth look at genetic counselor development across developmental levels. In an unpublished dissertation, Zahm (2009) investigated and proposed a preliminary model of genetic counselor career development.

Zahm’s (2009) investigation is important as an initial quest into genetic counselor professional development. Her study considered what constitutes professional development for genetic counselors, how it occurs, what facilitates or impedes it, and the role of experience. She also compared development of genetic counselors to that of psychotherapists using theories of psychotherapist development described by Skovholt and Ronnestad (1992), Ronnestad and Skovholt (2003) and Orlinsky et al. (2005).

Zahm’s results culminated in a proposed model of professional development. The model suggests that genetic counselors’ professional development is on-going across the professional lifespan, the components of development mutually influence each other, that development may follow positive and negative paths, and that genetic counselors’ professional and personal lives mutually influence each other (Zahm 2009).

With a purposeful sample, Zahm (2009) conducted telephone interviews with 31 genetic counselors. She also asked them to rank 15 influences on professional development previously utilized to study professional development in psychotherapists (Orlinsky et al., 2005). Zahm (2009) divided her sample of 34 into three groups, based on experience levels of novice (0-5 years of experience, 10 participants), experienced (6-14 years, 12 participants), and seasoned (> 15 years, 12 participants). The seasoned group had a mean of about 22 years of experience. (Mean average years of post graduate

experience for the total sample was just over 12 years.) As with the present study, analysis was completed using a modified version of Consensual Qualitative Research (Hill et al., 2005; 1997).

Zahm's (2009) qualitative investigation considered professional development for each group, and also cross-sectionally by comparing the three levels of post-degree experience. Zahm extracted three interactive components of genetic counselor professional development from the data. They included 1) Being a Clinician--the genetic counselors' view of their clinical work, including what it means to help, what constitutes success in genetic counseling, difficult sessions, the impact of memorable patients or cases on their practice; 2) The genetic counselors' View of the Profession, which included their perception of the field as a whole and the parallel process between their own growth and that of the field of genetic counseling, including adjusting expectations of themselves and of the field; and 3) a component encompassing professional identity such as turning points, views of professional development, goals, personal influences on professional development, and career satisfaction or dissatisfaction.

Within the theme of Being a Clinician, emerging developmental themes indicated that genetic counselors' perception of what it means to help changes across their careers from being information and agenda-driven, to focusing more on patients, such as attending to psychosocial aspects and emotions. It also included the ambiguity and uncertainty surrounding what constitutes success in genetic counseling, with results indicating that as they develop in their careers, genetic counselors view success through a more psychosocial lens and attend more to patients' emotions (Zahm, 2009). This theme also included difficult sessions such as encountering patient anger and dissatisfaction,

genetic counselors' emotional reactions, cultural and linguist differences, and learning to cope with giving bad news. Overall, seasoned participants seemed to experience a wider range and depth to their experiences and more willingness to acknowledge that they may not know whether or not they have succeeded with a patient (Zahm, 2009).

In terms of their view of the profession, the second theme, genetic counselors offered positive and negative views, including adjustment of their expectations of themselves and the profession, growth in seeing themselves as part of a treatment team, and importance in extending genetic counseling (Zahm, 2009).

The third theme focused on genetic counselors view of their roles as genetic counselors and the influence of their personal life on professional development. Participants also discussed turning points and catalysts for growth, continued professional development, motivation for remaining in the field, career satisfaction or dissatisfaction, experiences of personal influence on professional development (Zahm, 2009).

Findings (Zahm, 2009) suggested that the developmental process for genetic counselors occurs throughout the professional life span, that each component of professional development mutually influences the others, and that there are positive and negative avenues of development. Findings suggest that professional development for genetic counselors occurs gradually, over time, with "occasional bursts of 'defining moments'" (Zahm, 2009, p. 179). Genetic counselors' development is influenced by years of experience, but also by the quality of the experiences, and how genetic counselors process and integrate experiences may be equally as salient. "Experience in combination with processing of that experience (through internal self-reflection, informal

discussions with colleagues, or other means) and integrating what one has learned into his/her practice constitutes professional development" (Zahm, 2009 p. 179).

Over all, clinical work had quite an influence on genetic counselors development at all experience levels (Zahm, 2009). Additionally, of Orlinsky et al.'s (2005) 15 influences on professional development, Zahm (2009) found that experience with patients was rated as the top influence. Clinical experiences and reflection and integration of those experiences into their professional lives contributed to growth (Zahm, 2009).

In considering differences between the three experience groups, Zahm (2009) reported emergent themes of changes in 1) professionals' definition of helping over their careers with seasoned genetic counselors becoming more realistic, more confident, and less anxious about their limitations; 2) "seasoned participants describing a wider range and depth of experiences, particularly related to memorable patients and how those patients affected their later clinical work" (p.117); and 3) With more life experiences seasoned genetic counselors described more ways in which their personal lives had intertwined and affected their professional work.

Emergent themes across developmental levels (Zahm, 2009) included an increase focus on patients emotional needs and less focus on counselors' agenda; increased focus and attention on the patients psychosocial contexts and needs; defining success more in terms of the patient's individual needs; increased willingness to acknowledge whether they had succeeded with patients: and adjusted expectation of themselves and their role.

On the Development of Psychotherapists Common Core Questionnaire (Orlinsky, 2005) genetic counselors ranked relational issues—including those with patients and

those with colleagues—at the top of their list of influences, although Zahm (2009) noted some difficulties with the of the scaling of the questionnaire for genetic counselors.

Chapter 3

Methods

Overview

The most current definition of genetic counseling describes it as a "process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions of disease [through a process that integrates] interpretation of family and medical history to assess the chance of disease occurrence or reoccurrence, education about inheritance, testing, management, prevention, resources, and research, counseling to promote informed choices and adaptations to the risk or conditions" (National Society of Genetic Counselors' Definition Task Force, 2006, p. 77). The definition also includes performing psychosocial assessment to identify emotional, social, educational and cultural issues, evaluating the client or family responses to the condition or risk of occurrence, providing client-centered counseling and anticipatory guidance, and promoting informed decision-making (Biesecker & Peters, 2001.)

Yet to date, little published research has considered the *person* of the genetic counselor or what it might take to successfully provide counseling to meet the myriad of activities described above. Even less published research has considered what it might take to *excel* at genetic counseling--indeed, what might be involved in becoming a *master*

genetic counselor. If one envisions the "best of the best" (Jennings & Skovholt, 1999, p. 4) among genetic counselors, what might that person look like?

The purpose of the present study was to begin to describe the personal and professional qualities, characteristics, inspirations, strengths, and struggles of genetic counselors who have been identified as excelling in their work with clients.

Understanding the characteristics and behaviors of people considered to be the "best-of-the-best" within their respective fields can influence best practices, training, professional development, and ultimately the public served. In the discipline of genetic counseling, the concept of "expert" or "master" is, as of yet, unexplored. Therefore, this study draws upon theoretical frameworks in related fields to inform its methods and specific interview questions.

In short, this research explored the question: *What are the characteristics of "master" genetic counselors?* Since little research has been published on what it means to be an "expert" or "master" genetic counselor, qualitative research is appropriate to help lay the groundwork for future studies.

Design

Qualitative methods offer one way to begin to define what it means to be a "master" or "expert" genetic counselor. Qualitative methods are considered appropriate in the discovery and exploration phase of research, when studying areas in which little research has previously been published (Hill, Thompson & Williams, 1997; Jennings & Skovholt, 1999; Marshall & Rossman, 1999; Patton, 1990) and to generate theory about the counseling process (Rennie, Phillips, & Quartaro, 1988).

Qualitative research allows for immersion in the data and for themes to emerge without imposing preconceptions or preexisting expectations. Rather than the "objectivity" of quantitative research, qualitative research seeks "trustworthiness" and "authenticity" while allowing for themes to emerge from the data (Patton, 2002). Further, inductive methods of analysis allow for explanations that fit with observations rather than vice versa. These methods attend to characteristics rather than causes (Lippman-Hand & Frazer, 1979), and therefore, qualitative analysis often illuminates phenomena that might be overlooked by more quantitative*, apriori* methods (Banister, Burman, Parker, Taylor, & Tindall, 1994).

Although no previously published studies address the concept of master genetic counselors, qualitative methods have been successfully implemented in previous studies exploring the experiences and perspectives of genetic counselors in general (e.g., Benoit et al., 2007; Hendrickson, McCarthy Veach, & LeRoy, 2002; Lafans, McCarthy Veach, & LeRoy, 2003; Runyon, et al., 2010; Schoonveld, McCarthy Veach, & LeRoy, 2007). Additionally, qualitative methods using a pre-defined group of well-regarded professionals have been adopted previously in studies of master psychotherapists (Jennings & Skovholt, 1999; Skovholt, 2005; Skovholt & Jennings, 2004; Skovholt & Jennings, 2005) social workers (e.g., Fook, Ryan, & Hawkins, 2000), physical therapists (e.g., Jensen, Gwyer, Shepard & Hack, 2000) and nurses (e.g., Benner, Tanner, & Chesla, 1992). Therefore, a qualitative design and qualitative analysis was chosen as best suited for the present study.

The present study was patterned after Skovholt, Jennings and colleagues' seminal exploration of master psychotherapists (Jennings & Skovholt, 1999; Skovholt, 2005;

Skovholt & Jennings, 2004; Skovholt & Jennings, 2005). However, whereas Skovholt and Jennings used a grounded-theory approach, this investigation is based on the Consensual Qualitative Research (CQR) method (Hill et al., 1997; Hill et al., 2005). The CQR method offers the advantages that it is systematic and replicable, and it can be used to describe individual cases as well as across cases (Hill et al., 1997). The primarily components of CQR include open-ended, semi-structured data collection techniques, often via interviews. Interviews allowed this investigator to immerse herself in the details of the genetic counselors' stories and to "listen deeply and intently" to their "experience and perception" (Patton, 2002, p. 53). Another strength of the CQR method is its use of several judges during the data analysis process and an auditor to check the work of the primary team. Involving a team of researchers in the analysis process fosters multiple perspectives in arriving at judgments about the meaning of the data as they are distilled into domains, core ideas, and finally, cross-analysis of the cases. Overall, CQR carries the benefits of being exploratory, discovery-oriented, constructivistic and comprehensive (Hill et.al, 2005).

Participants

In order to tap potential expertise, this study sought information from genetic counselors with a rich experience base and who were considered exemplary clinicians by their peers. To build that homogenous sample of exemplary genetic counselors, this investigator used a purposeful sampling method (Patton, 2002); a method which was previously effective in studies of master therapists (cf. Jennings & Skovholt, 1999). Such "information rich cases" are well-suited for studies seeking depth, insight, and an "inside understanding" from participants' perspectives (Patton, 2002, p. 230). In effect,

the intent was to invite exemplary genetic counselors to begin to describe the characteristics of being an expert within their field; to begin describing the characteristics of being a master genetic counselor.

Upon approval from a University of Minnesota Institutional Review Board, this investigator began a two-step participant recruiting process. She first asked leaders in the field of genetic counseling to nominate people they admired as exemplary genetic counselors. Next she invited these nominees to participate in the study. In the first recruitment step, letters were emailed to leaders in the field of genetic counseling asking them to nominated possible participants for the study (See Appendix A). For the purpose of this study she defined "leaders in the field" as past-presidents of the (NSGC), and/or recipients of one of two national awards presented annually by the NSGC the Jane Engelberg Memorial Fellowship and/or the Natalie Weissberger Paul National Achievement Award. [The Jane Engelberg Memorial Fellowship is a competitive, peer-reviewed grant that promotes professional development of individual certified genetic counselors by funding projects targeted toward the improvements of the practice of genetic counseling. This award has been presented annually since 1991 and carries a $50,000 grant. Applicants must be board certified genetic counselors (www.nsgc.org). Nominees for The Natalie Weissberger Paul National Achievement Award are solicited annually from the NSGC's membership, and honor one outstanding member who has served the NSGC with "exemplary national achievements and volunteer activities on behalf of NSGC and the profession" (www.nsgc.org). Fifteen genetic counselors have received The Natalie Weissberger Paul National Achievement Award since its establishment in 1994].

The investigator emailed a letter to 54 individuals who met this criterion. The email described the study and invited the leaders to nominate as potential participants genetic counselors whom they would: (a) offer as a referral to a family member or close friend because they considered her or him to be among the "best of the best" genetic counselors or (b) would have full confidence in seeing for their own genetic counseling or (c) whom they consider to be a master genetic counselor. Additional criteria included that the study participants were genetic counselors certified by the American Board of Genetic Counseling, and they either were currently practicing or had practiced within the past two years. These criteria were informed by a review of the expertise literature in related disciplines.

Of the 54 emails sent to leaders, three emails were returned and six leaders responded. The respondents nominated a total of 27 genetic counselors. There were no duplicates among the nominees. The investigator subsequently invited the 27 nominees via email (See Appendix B) to participate in the study during the second step of the recruitment process. The email explained the nature and purpose of this study, procedures, confidentiality, right to withdraw, and the nonjudgmental nature of the study (Hill et al., 1997). The email also included contact information for questions and concerns. Participants were informed that interview questions would be emailed to them in advance to allow for reflection and thus deeper insight in the data. The potential participants were invited to contact the investigator or return the form if they were interested in participating. A second reminder invitation was sent to those individuals who did not respond to the initial invitation.

Of the possible 27 participants, six did not respond to the invitation(s), two declined to participate, three were not eligible (due to no longer seeing clients), and one did not follow through on an interview after initially agreeing. Thus the study sample consisted of 15 participants. For CQR research, Hill and colleagues (1997) recommend a sample size of 8-15 participants. This number allows for a sample small enough to examine each case intensely, but large enough to consider findings within the group as a whole. Hill et al. (1997) further argue that this sample size is sufficient to reach saturation (redundancy) of the data. Therefore, the investigator determined that the sample size would be sufficient.

Instrumentation: Interview Protocol

Each participant was asked to respond to 16 demographic questions (See Appendix C) regarding their age, ethnic/racial background, gender, education, years of genetic counseling experience, primary work setting, years of genetic counseling experience, specialty area(s), and other professional background. The investigator asked the demographic questions over the phone and at the end of the interview, in all cases.

This method has been used extensively in previous research on mastery in other fields (cf. Jennings & Skovholt, 2004). In-depth interviews allow for the capture of personal perspectives (Marshall & Rossman, 1999 Patton, 2002), produce thick descriptions, and encourage elaboration (Rapley, 2004). Additionally, semi-structured interviews allow respondents to describe what is meaningful and salient to them, in their own words, and from their own perspectives, without being forced into categories preselected by the researcher (Patton, 1990, 2002). In semi-structured interviews, each question is asked in approximately the same order with prompts, as necessary, for

elaboration and/or clarification (Patton, 2002). Questions used in the present study were based very closely on those developed by Skovholt and Jennings (1999) for their study of master therapists. Skovholt and Jennings' (1999) questions were designed to "elicit information concerning the characteristics of master therapists" (Skovholt & Jennings, 2004, p. 151).

The interview protocol consists of 16 questions. Hill et al. (2005) recommend a rate of eight to ten questions per hour. However, 16 questions were necessary in order to pattern them closely to those used by Skovholt and Jennings (2004) in their study of master practitioners in the field of psychotherapy. Questions were also augmented based on literature reviews within the field of genetic counseling, as well as reviews of literature on expertise in social work (e.g., Nilsson, Ryan & Miller, 2007), nursing (e.g., Adams et al., 1997), and other medically oriented fields. Questions inquired about distinguishing characteristics of master genetic counselors; necessary attitudes, values and traits; how master counselors develop; the impact of genetic counseling on the counselor; positive and negative experiences; what constitutes success; and inspirations and motivations. The questions were piloted on one certified genetic counselor who was not a participant. Based on her feedback, wording of a few questions was clarified. Additionally, after the first two interviews, the interviewer varied the question format by inverting the order in which genetic counselors were asked about a successful case and an unsuccessful case (Questions 9 and 10). This resulted in a smoother conversation leading into the question about their professional inspirations, and also allowed participants to conclude their interview with a success story rather than one of challenge.

Procedures

Potential participants who agreed to be included in the study were asked to return an informed consent form included in the email (Appendix B). This investigator then contacted each participant via email to set up a telephone interview at a date and time of the participant's convenience. Questions were emailed to participants once they had scheduled an interview to provide an opportunity for reflection on the questions and their responses.

All 15 interviews were conducted by this investigator in order to encourage consistency and promote trustworthiness, which support rigor in qualitative research (Hill et al., 1997). They took place by telephone during the first half of 2010, with most conducted during the summer months. Interviews took place by telephone, as opposed to face-to-face, in order to obtain a national sample of genetic counselors. Hill et al. (2005) contend that telephone interviewing is an adequate method of data collection for the CQR method, and in fact, may allow for more open disclosure by participants who may feel less need to present socially desirable responses.

In qualitative research, the researcher is both the instrument of data collection and that of data interpretation (Hill et al., 1997; Patton, 2002). As such, the investigator introduced herself as a doctoral candidate with a master's degree in mental health counseling who has conducted previous research on the process of genetic counseling, including observing more than a dozen genetic counseling sessions. Additionally, she is experienced in conducting semi-structured interviews for research purposes and in practice settings as a mental health counselor.

As much as possible, the interviewer strove for an "empathically neutral stance" during the interviews (Patton, 2002, p. 50) and to maintain the stance of a trustworthy reporter (Hill et al, 2005). Within this interview format, the researcher sought to develop a balanced approach in establishing the rapport necessary to encourage participants to speak freely, while at the same time keeping in mind the effect positive reinforcement can have on a mutually created discussion (Patton, 2002). The investigator did use minimal encouragers, summary statements, and follow-up questions to encourage participants to expand upon their views and meaning, but generally she refrained from introducing topics not included in the protocol questions. The investigator attended to "respecting how the participant frames and structures the responses" (Marshall & Rossman, 1999, p. 108), while encouraging participants to express meaning and understanding of phenomena from their own perspective (Hill et al., 1997). This interview format flows with the thinking that experiences are non linear and allows participants to make connections (Hill et al., 1997). Also, asking participants the same questions, in the same order, allows for comparisons across responses (Hill et al., 2005; Patton, 1990).

All participants agreed to have their interviews audiotaped and transcribed. Each session was audio recorded in its entirety. Following each session, the researcher made field notes regarding impressions and interactions. Interviews ranged from 34 to 77 minutes, with a median of 57 minutes. The average length of the interviews was also 57 minutes. None of the interviews seemed rushed, and participants seemed to have ample time to express themselves at length according to their preference. One interview was interrupted by a fire alarm at the genetic counselor's place of employment. The

counselor left the building and called back upon returning about 20 minutes later and completed the interview.

Data Analysis

Data were analyzed using a modified version of CQR (Hill et al., 1997), an inductive analysis method. In inductive analysis, investigators immerse themselves in the details and specifics of the data in order to discover themes. As mentioned previously, this approach is regarded as appropriate when studying areas in which little prior research has been conducted (Patton, 1990) and in order to generate theory about the counseling process (Rennie, Phillips, & Quartaro, 1988).

In order to remain as close to the data as possible (Hill et al., 1997), the investigator transcribed tapes of all sessions verbatim, including false starts, nonsequitors, fillers, pauses, and non-word responses such as laughter, and noted parenthetically within the transcripts observations she made during the sessions. Personally transcribing the interviews allowed the investigator to immerse herself in the interviews as an observer, becoming more familiar with the data.

Hill et al. (1997) specifically identify CQR as appropriate for analyzing phenomena that occur infrequently, involve inner experiences, and for studies of "how things came to be," (Hill et al., 1997, p. 520), all of which describe characteristics of the present study. The CQR method consists of the following four steps: First, the research team develops "domains" or topic areas which are rationally derived from the data. Next, the team constructs "core ideas," or summaries of the content in each given case. This is a boiling down, or abstraction, of the essence of what the interviewee has said, but it stays close to explicit meaning. The domains and core ideas are checked by an auditor,

and finally the research team engages in cross-case analysis. Cross-case analysis involves all the core ideas from the participants and considers which domains are represented across the sample.

Similar to the *grounded theory* approach used by Jennings and Skovholt (1999), CQR is a systematic, phenomenological approach, which allows important concepts to arise inductively from the data. Both also utilize the *constant comparative method* in analyzing the data, an approach which allows categories to emerge as the researchers gain understanding of the data. In addition to studies of master therapists, a grounded theory approach has been found effective in the study of the process of psychological counseling (Rennie, 1994; Rennie et al., 1988) and has been suggested as a method of understanding the psychosocial processes of genetic counseling (Beeson, 1997; McAllister, 2001).

Both CQR and grounded theory methods allow categories to emerge from the data and these methods allow categories to evolve. Additionally, CQR offers the advantage of a multi-person team for analyzing the data, potentially reducing the bias introduced by any one team member. This investigator recruited a team of two research assistants, master's students in a psychological counseling program, both of whom had experience in counseling. One research assistant also had considerable experience coding qualitative research. A fourth team member, a licensed psychologist who conducts research on genetic counseling, served as auditor.

This investigator trained the research assistants in the principles and methods of CQR. Training included approximately four hours reviewing Hill et al.'s (2005) article explaining the method and a handout outlining the method prepared by the investigator, as well as hands on experience in going through the first couple of interviews in detail

and with explanation of the method, until the team had a solid understanding of the application of the system. The team discussed possible biases, including being more familiar with mental health counseling than with genetic counseling, and personal reactions to some of the interviews. The team held regular consensus meetings, and this investigator attempted to create a cohesive team within which members felt free to disagree as well as collaborate. Discussion was always respectful, sometimes intense, and always well-thought out with team members providing considerable insight.

In the modified CQR analysis processes for the present study, all team members independently coded all material for five of the transcripts. Following independent coding of each individual transcript, the team met to discuss and reach consensus on the coding (Hill et al., 1997). Applying multiple perspectives to the data helps reduce any one individual's personal bias, thus adding rigor to the study (Hill et al., 1997). In this collaborative way, domains (topic areas) were constructed, evaluated, and reconstructed until consensus was reached. Rather than assigning domains based on interview questions, the team allowed domains to arise from the interview transcripts (Hill et.al, 2005). Some remained defined by the interview questions, but others evolved within the questions. Domains changed, with some added, some deleted, and others combined in the process as themes arose from the data.

After coding the first five interviews, each of the three team members had a solid grasp on the method, so each subsequent interview was coded independently by just two team members. This investigator coded all 15 interviews, with each master's student coding an additional five. In their review of studies conducted using CQR methods, Hill et al. (2005) conclude that a "rotating team approach" is adequate for analysis, provided

all team members remain immersed in the data. In the present study, all team members read each interview, reviewed the coding of all interviews, and all interviews were discussed in full until consensus was reached.

Next, a similar process was applied to further summarize the content of each domain, a process of “boiling down” or “abstracting” each domain (topic) into core ideas (Hill et al., 1997). In a final level of analysis, the data auditor reviewed the “rationally derived domains” (Hill et al., 1997) and core ideas for consistency and sense. Any disagreements were discussed until consensus was achieved.

Chapter 4

Results

The purpose of the present study was to begin to describe the characteristics of master genetic counselors. A modified version of Consensual Qualitative Research (CQR; Hill, 2012; Hill, Thompson & Williams, 1997; Hill et al, 2005) was used to inductively extract themes, domains, and categories from transcripts of participants’ responses to interview questions. Illustrative direct quotations from participants are included in this chapter. All quotations are exact other than minimal editing for grammatical clarity.

Participant Characteristics

Participants’ demographics are summarized in Table 3. Participants included 12 women and 3 men. Twelve self-identified as Caucasian/European-American, and four

identified themselves as belonging to one or more groups representing racial/ethnic diversity. Some participants identified with more than one racial/ethnic category. Given the small sample size, all categories of racial/ethnic diversity were collapsed into one in order to preserve participant anonymity.

Participants' ages ranged from the low 30s to the mid 60s (specific age range is also not included in order to preserve participant anonymity). Their mean age was 51 years (Mdn = 57; SD= 9.6). The sample was drawn from the United States and Canada, and there was a fair amount of geographic diversity within the U.S., except for the southeastern part of the country. The 15 participants were currently working in 12 different cities located in 12 different states/provinces. The 15 participants had graduated from a total of 9 different colleges/universities. Nearly all had an MS degree, and several held additional degrees.

Participants were generally quite experienced, as shown in Table 4. They had a mean of 23.3 years of post-graduation genetic counseling experience (Mdn = 27 years; SD= 10.44; R: 6-36 years).

All were currently practicing genetic counseling, with 11 working full time, and four working part time, as shown in Table 5. In their current positions, participants reported seeing a mean of 9 patients per week; however the range was quite wide, from one patient per week to almost 18 (Mdn = 7; R: 1-17.5). The broad range reflects counseling setting as well as full and part-time practice. Participants were also involved in a number of non-patient contact areas of genetic counseling, as indicated in Figure 1. Nearly all of the participants were engaged in teaching and/or supervision to some degree at the time of the study. Many were also engaged in research. At the time of the study,

most participants were working in hospital or university-related settings. Participants worked in a variety of practice specialties, many working in more than one area. Participants reported currently working in a total of nine

Table 3. Participant Demographics N=15

Variable		***n***
Gender		
	Female	12
	Male	3
Racial/ethnic identification		
	European-American/ White	12
	Racial/ethnic diversity	4
Age		**Years**
	Mean	51
	Range	Low30s mid-60s
	Median	51
	SD	9.6

Note. [a]To protect participants' anonymity, all types of racial and/or ethnic diversity identified by participants were collapsed into one category.
Total *n* is > 15 because some participants identified with more than one category.

Table 4. Participants' Years of Genetic Counseling Experience

Mean	23.33
SD	10.44
Median	27
Range	6-36

Table 5. Patient Contact

Average Number of Patients Seen Per Week	***n***
Mean	9
SD	5.38
Median	7
Range	1-17.5

Percent of Time in Patient Contact Per Week	***%***
Mean	53.8
SD	34.2
Median	50
Range	5-100

Full-Time vs. Part-Time Employment	***n***
Full-time	11
Part-time	4

different areas of practice or specialization, with cancer and prenatal genetic counseling being the most frequent.

Current practice specialties are not reported because of the small sample size in order to protect participants' identities. Nonetheless, consideration of specialties across the participants' careers gives some indication of the breadth of the sample. Across the span of their careers, participants had specialized in many areas, with most having worked in prenatal and/or pediatric genetic counseling, followed by cancer genetic counseling. Cumulatively, Table 6 shows areas in which participants are currently working or have worked previously.

Table 6 Participants' Current and Previous Areas of Practice Specialization (*N*=15)

Area of Practice	***n***
Prenatal	11
Pediatric/adolescent	7
Cancer	6
Specialty Clinics	6
HD-Adult Neurology	5
Alzheimer	≤3
Hearing/Vision	≤3
Hematology	≤3
Metabolic	≤3
Molecular	≤3
Other	≤3

Note. Many participants endorsed more than one practice area.

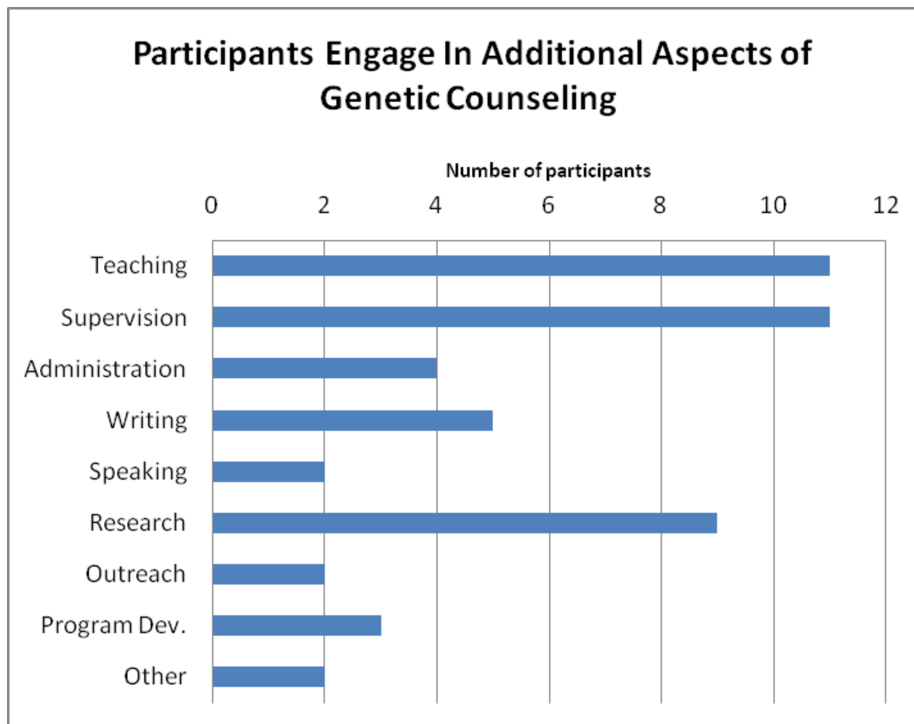

Figure 1. Participants' participation in other aspects of genetic counseling.

Clinical Impressions of Participants' Interviews

Including clinical impressions in qualitative research helps provide context for interpreting and understanding the data (Burkard, Knox & Hill, 2012). For the present study, all interviews were conducted by telephone and by this investigator. Interviews were scheduled at the convenience of the genetic counselor participants. They ranged from 34 minutes to 77 minutes (mean=57 minutes; Mdn=57 minutes). Participants chose

their setting for the interview, and all talked from their workplace. As much time as necessary was provided by the investigator for each interview. None of the interviews seemed rushed or extraordinarily extensive. One interview was interrupted by a fire alarm at the participant's place of work, but was resumed shortly thereafter and completed normally.

In order to provide time for participants to reflect on their responses, the investigator had provided the interview questions in advance. Participants varied in the degree to which they reviewed the questions ahead of time, with some noting they had written down responses to which they referred as we talked, while others noted they had not reviewed the questions at all. Several participants commented on some redundancy in the questions. Some asked questions regarding the study's methodology, and some noted the importance of the study.

Overall the interviews seemed conversational, and most participants talked at length and seemed to enjoy "telling their story." They were quite reflective in their responses and seemed to enjoy the opportunity to talk about their work and the profession of genetic counseling. They were very forth-coming and quite engaged and elaborative. Participants often connected their thoughts back to previous questions, or wondered aloud about some of their own thoughts during the interview. Participants seemed to have no concern with disclosure. They were very open to initial questions as well as follow up questions, including those addressing personal or difficult experiences. They seemed quite comfortable being emotionally expressive.

In several interviews this investigator disclosed her age in conjunction with participants' discussion of their own age or the length of their careers. This seemed to build rapport and increase the richness of their responses.

Data Analysis

Data analysis yielded a total of 14 domains and 75 total categories divided among the domains. In accordance with CQR methods, categories consisting of data from all participants or from all but one participant are labeled *general*; categories including data from half of the participants up to the cutoff for the general category are labeled *typical*; categories with data from at least two and up to half the participants are labeled *variant;* categories including only one participant are labeled *rare* (Hill, 2012). Thus, for this sample of 15 participating master genetic counselors, *general* categories include data from 14-15 participants; *typical* from 8 to 13, and *variant* 2 to 7 participants. Table 7 enumerates domains, and the frequency of categories. Throughout this section, *n*'s refer to the number of participants endorsing each category, which provides a look at the representativeness of each category to the sample as a whole. Because participants' responses were complex, they often were classified multiple times into domains and categories. Thus, *n*'s for categories within a given domain may total greater than the number of participants represented by the domain.

Table 7. Results: Themes, Domains and Categories

Results: Themes, Domains and Categories

THEME A. PERSONAL CHARACTERISTICS OF MASTER GENETIC COUNSELORS

Domain		*Category*	*n*	*Frequency*[a]
1	**Defining Traits and Attitudes**			
		Insatiable curiosity, love of learning, life-long learning	14	*General*
		Constantly "seeking and searching"	9	*Typical*
		Additional characteristics	9	*Typical*
		Self-awareness	8	*Typical*
		What is a master genetic counselor? "Gee, I don't know!"	8	*Typical*
		Passion and "dynamic commitment"	7	*Variant*
		Going "above and beyond"	6	*Variant*
2	**Developmental Influences**			
		Colleagues	13	*Typical*
		"Infectious excitement": the impact of mentors	10	*Typical*
		The influence of family of origin	7	*Variant*
3	**Master Genetic Counselor Development**			
		A developmental process	15	*General*
		Quality of experience trumps quantity	13	*Typical*
		Learning from the patients	11	*Typical*

		Experience required	10	*Typical*
4	**The Person of the Master Genetic Counselor**			
		Counselor use of self: Their personality is their style	14	*General*
		Use of self: genuine, authentic, and "comfortable in their own skin"	9	*Typical*
		The importance of fit	9	*Typical*
		Professional self matures over time	6	*Variant*
		A merging of personal and professional selves	5	*Variant*
5	**Self-Reflection is Key**			
		Realistic expectations and awareness of limitations	14	*General*
		Crucial, dynamic, and continuous	11	*Typical*
		Leads to insight and growth	8	*Typical*
		"Confidence and grace"	8	*Typical*
		Multicultural awareness	8	*Typical*

THEME B. MASTER GENETIC COUNSELORS' RELATIONSHIP WITH PATIENTS

	Domain	*Category*	*n*	*Frequency*
6	**A Collaborative and Interactive Relationship with Patients**			
		Fully present and empathically involved	14	*General*
		Rapport is "crucial"	8	*Typical*

		Equalizing the power differential	8	*Typical*
		The pedigree: "the ultimate rapport building tool"	7	*Variant*
7	**Attuned to Multiple Layers and Complexity**			
		Aware of session dynamics	13	*Typical*
		Flexibility and "meeting patients where they are"	12	*Typical*
		Tailoring salient information for individual patients	8	*Typical*
		Sharing information gained through clinical experience	2	*Rare*
8	**Inspirations**			
		Patients	12	*Typical*
		Deep personal meaning from the work	12	*Typical*
		Science, learning and new information	8	*Typical*
		Patients' resilience and courage	7	*Variant*
		Colleagues	4	*Variant*
9	**Emotional Impact**			
		An emotional impact: loss, sadness, helplessness, and communicating bad news	15	*General*
		Managing the emotional impact: emotional boundaries and compartmentalizing	10	*Typical*
		Additional coping/self-care strategies	8	*Typical*
		Monitoring for compassion fatigue	7	*Variant*
		Managing the emotional impact: separating personal and professional lives: work is work and home is home	6	*Variant*

	Positive impact on personal life	3	*Variant*

THEME C. SUCCESS IN GENETIC COUNSELING

Domain	Category	*n*	*Frequency*
10 **What Constitutes "Success"?**			
	Interactive engagement	12	*Typical*
	Success is multi-faceted	11	*Typical*
	From the patient's point of view	10	*Typical*
	Trust and relationship	10	*Typical*
	Interactive communication	9	*Typical*
	Success can be ambiguous	7	*Variant*
	Information leads to informed decisions	6	*Variant*
	Providing support and facilitating coping	5	*Variant*
	Patients integrating knowledge	5	*Variant*
	Verbalizing intuition and encouraging feedback	5	*Variant*
	Patients gain insight, perspective, understanding, or find meaning	5	*Variant*
	Fostering empowerment, efficacy, and competence	4	*Variant*
	Connection and attunement	3	*Variant*

11	**Challenging Cases**			
		Angry, aggressive, or confrontational patients/families	10	*Typical*
		Unengaged patients	9	*Typical*
		Reflecting on difficult cases	7	*Variant*
		"Button-pushers"	6	*Variant*
		Chaotic sessions	4	*Variant*
		Personality styles	3	*Variant*
		Patients' strong reactions to bad or ambiguous news	3	*Variant*

THEME D. THE VIEW OF THE PROFESSION

	Domain	*Category*	*n*	*Frequency*
12	**Art vs. Science**			
		Blend of art and science	8	*Typical*
		Primarily science	4	*Variant*
		Primarily art	4	*Variant*
13	**What Does "Psychosocial" Mean in Genetic Counseling?**			
		A range of definitions	15	*General*
		Psychosocial perspective is essential	7	*Variant*
14	**The Changing Landscape of Genetic Counseling**			

Evolution of the profession	9	*Typical*
Pioneers' perceptions	8	*Typical*
The impact of healthcare economics	7	*Variant*

Note. [a] Using Hill et al. (2012) definitions**,** *General* = data from 14 to 15 participants; *Typical* = data from 8-13 participants; *Variant* = data 2-7 participants*; Rare* = data from less than 2 participants

Domain 1: Defining Traits and Attitudes

This domain primarily derived from questions asking participants what, in their opinion, distinguishes a great genetic counselor from a good genetic counselor, and what they regard as the necessary attitudes, values or traits of a master genetic counselor.

Category 1. What Is a Master Genetic Counselor? "Gee, I Don't Know!" (*n=8*)

Participating master genetic counselors found the concept of "master genetic counselors" to be novel and intriguing, but difficult to define. Some noted they either had not previously considered the concept, or that it seems like a new concept. Several expressed humility that they would be included in such an elite group.

> What distinguishes a great genetic counselor? That's an interesting question; that's a really hard question. I was thinking about that, and I don't know!
>
> Boy, what distinguishes [a master genetic counselor]? Gee, I don't know. As I say it's still a semi mystery to me why I'm chosen [to participate in this study].
>
> If I had to say, what defines it? I guess, that's hard.
>
> I don't even know if we have a good definition of what these "master" people are and what it is they do that makes them stand out.
>
> Until [recently] I never really thought about it.

Characteristics that might make a genetic counselor stand out, or that might distinguish them from a genetic counselor who was good, but not among the "best of the best," were also difficult for participants to describe immediately. A couple of individuals related the concept of "mastery" to clinical work; and they made a distinction between mastery in non-clinical areas and mastery in clinical areas, noting the necessary traits differ somewhat.

> That should be a small number of people.
>
> I've usually heard the word master genetic counselor used in the context of clinical counseling. There are definitely a set of genetic counselors with mastery in non-clinical areas, but they might have a somewhat different set of traits. So I'm thinking of masters only in the clinical sense.

Three of the master genetic counselors noted lack of an objective definition or outcome measures to evaluate master skills or traits, and consequently to identify which genetic counselor might meet those criteria. They also noted the lack of opportunities to observe other counselors in action. To this end they contended they could not confidently say what might be distinguishing factors because they had not been able to observe and judge colleagues' practice for themselves.

> None of us know how each other counsel. We suspect!
>
> Well, I don't know [what distinguishes a master genetic counselor], because I haven't really observed or been able to judge for myself a lot of my colleagues' practice.

Category 2. Strong Passion For and a "Dynamic Commitment" to the Field (*n=7*).

When asked about defining characteristics or characteristics that might differentiate master genetic counselors from "good" genetic counselors, many of the participants identified passion, intellectual curiosity, going above and beyond, and

finding a niche, or having a piece, and sometimes more than one piece, in which they were very invested. They spoke of a "dynamic commitment" to the field of genetic counseling, and several framed commitment as an "investment" in the field. Others considered it a "calling," rather than "just a job."

> I think the very first thing [that distinguishes a master genetic counselor] would be a passion for what they're doing. So you can sit there and do what you're supposed to do, or else you can really be passionate about it and try to do it very well. Really having a passion for some aspect of it that gets you invested in it.

> Oh I love it. I absolutely love it. I mean I am so grateful. I'm so grateful to be a genetic counselor. I have grown up; I've absolutely grown up as genetics has grown up. To us—I know this sounds ridiculous—it was a calling**.** It really was**.**

> A great genetic counselor is passionate about genetic counseling. At first I was thinking passionate about something, and, well I think it's really genetic counseling we're passionate about.

> There's sort of the excitement. That this is an exciting field and they want to be a part of that.

> Besides my [children], the genetic clinic is my baby. I've been doing this for almost 30 years. This…clinic is my baby.

When they described characteristics of master genetic counselors, these participants sometimes referred to themselves, but interestingly, they also talked in terms of colleagues they respected and students they viewed as having the potential to become master genetic counselors.

> [Name] and [Name] are some of the smartest women I know; they are so smart! They have big brains! But they're also passionate about what they do. They care deeply.

Several genetic counselors framed their discussion about the distinguishing passion in terms of students they work with whom they consider "exceptional." They compared their students to themselves at that level of development and delighted in

students who share their passion. Some talked about seeing themselves in these "go-getters" whom they describe as having an intuitive sense of the how-to's of the field, not needing step-by-step instructions, and who are motivated to seek out and learn all they can.

> It's that spark. It's the 'Do I have to tell you what to do?' or do you sort of intuitively want to do this well, do everything you can to do it well, and maybe you screw it up and make a mistake. It's the student who comes in and says, "I didn't really know how to do this". You can really sense that excitement and passion. Like, "I want to do this for my life, what do I need to do?" They seek out feedback. People really didn't have to tell me to do X, Y and Z because I really wanted to do it! And so I just went out and did it, because this is what I want to do with my life!

Category 3. Going "Above and Beyond" (*n=6*).

Passion and commitment, investment and willingness to engage in the profession, motivate master genetic counselors to put forth extra effort, what several termed "going above and beyond." This characteristic can distinguish those counselors who invest in understanding their patients' experiences in a way that provides insight. One counselor made the distinction between genetic counselors who say "Hey, I'm here 8 to 5, do my job and go home" vs. those who are willing to get involved in patient organizations or education or attend clinics to which they might not necessarily be assigned. Master genetic counselors are driven to know their patients beyond their disease, to know their story, in order to help. They are dedicated to their patients.

> I think after you see a few people and you realize, I can just stuff information at them, some standard stuff, or I really want to get to know what this is, and really get these people's story, and I think that's sort of the point where you say, 'I'm going to go out and do some more'.

> It's those things that I think really sort of get you [engaged] in those communities and really get a sense of the experiences of these families and people. To really

> understand what the experience is, you have to do some of those things that are not necessarily part of your job but give you that insight.
>
> The great genetic counselors go the extra steps.
>
> I think I always go the extra mile, but I think sometimes there's an extra, extra mile. I'm learning maybe I shouldn't be quite so good!...Which is another thing that I think you'll find with these genetic counselors, they just can't say no to stuff. It's a plus and a minus.

Category 4. An Insatiable Curiosity, Love of Learning, Life-long Learning (*n=14*)

One participant described a "thirst for information" and the pleasure of being "intellectually stretched" that often extends beyond one's specific specialty area. Master genetic counselors are "perpetually learning and experiencing," as one individual commented. They constantly seek out and learn new information as life-long learners. Learning is an inspiration and motivation, and it is fueled by an innate curiosity.

> There's a fascination with the information piece for genetic counselors.
> I always wanted to-- I don't want to say 'be excited,' because you're going to think that I walk around going, 'Oh this is cool,'-- but to really derive some innate pleasure from learning.
>
> Learning new information. Science, figuring out something, some really complex concept-- that inspires me. Learning. Learning really inspires me
>
> And I love to learn! We get to do so much learning. You know, every week I get to do a lit search, because, I better see if something new has come out! And that's great!

Participant master genetic counselors talked about on-going learning and wanting to better themselves. The people they consider masters are always searching and seek to learn from every experience.

> You don't just stop learning at graduation---well, you can't. I mean, even when you go to the annual education conference, and I know there's a lot of senior

genetic counselors who go to the education conference every year and say, 'I'm not learning anything this year,' and I'm like "Well then that means you're not listening. Because there's so much you can learn."

So when I think about the people who I admire as mentors and great counselors, they're people who are always questioning, always searching, wanting to learn from every case and every experience. Sort of bettering themselves.

One of the things that I've really liked about my job is that it's a moving target. And that the knowledge base is always changing, and the things that you said to somebody about this condition three years ago may be entirely wrong, and our whole understanding of it is 180 degrees in the other direction. That sort of intellectual fascination, both with the information base and with people's responses to data and their situation has been remarkable.

The intellectual challenge of genetics, with thousands of genetic disorders, there isn't a day that has gone by in 30 years that I haven't learned about a new genetic syndrome. Now that's amazing. That's amazing. So patients call up and they'll say I'm being referred because of syndrome [name] and… in my mind I'm thinking, 'Oh, it can't be.' But see, now I know enough not to say that any more. I look it up on Ovid [an online, searchable bibliographic database including journals in the health sciences] and there it is! And I've never heard of it before!

Often the drive for learning new information extends beyond the genetic counselor's area of specialty.

I find myself really paying attention to what is happening in a variety of genetic counseling [specialties]."

One of the things I've always done--and for completely selfish reasons--is to learn everything about the field that I'm working in. Way beyond genetics.

Beyond taking in and learning information, master genetic counselors exhibit "Deep competence in knowledge" which they are able to translate into a form that their clients can use. Being a master genetic counselor requires "deep competence in the knowledge area," as one individual remarked, but also thoroughness and comprehensiveness in being able to judge the clinical value of information, and

excellence in *"critical thinking and at synthesis"* in order to use the information in a clinical setting.

> There's an integration of the information piece into people's everyday lives. I think most genetic counselors are going to have a lot of the same knowledge base. I think the distinguishing factor in my opinion is how that information is used skillfully in a session.
>
> This is a different concept here of translating information into a usable form…You know, we talk a lot about how patients, they're medically sophisticated or they're smart, or they're this or they're that, but you can lose even a medically sophisticated, highly educated client if you can't draw a logical picture for a client. The use of a logical train of thought. If you can have a good clear picture for a client, they'll be able to follow it, most of the time. And if you can't, they won't.
>
> Competence in the knowledge area almost goes without saying. This includes a scholarly approach that goes beyond standard sources to the ability--not just the ability, but the drive to do it.… you don't just go to some shorthand source that somebody else has done. You know how to go to the literature, do a comprehensive review, and make your own judgment about the value of what you find there. And bring that into the clinical situation.
>
> It's important to keep up with the education, keep current in the literature, to keep that knowledge base current and secure. To me it's like painting the scaffolding over and over; it's like you've got to keep it from rusting. You know you've got to put the fresh paint on those basics. So I think, kind of a constant rejuvenation of knowledge which is also one of the joys of this job, is because it's like 'brain candy' you get to learn new stuff all the time!
>
> I mean, a lot of this stuff, do I really know everything thing there is to know about [specific disorder]? No. But my patients don't need to know that**.** They just need to know that this is the Cadillac of genetic testing. And this is what we're going to do and this is how we're going to do it. And if I can make everybody I see understand just some basics the way I understand them, that's probably OK.

Category 5. Constantly "Seeking and Searching" (*n=9*).

These master genetic counselors seem to thrive on continual development and growth, what one described as "a dynamic seeking and searching." In additional to savoring information, master genetic counselors' seem to enjoy a challenge and when

they no longer find it in their current situation; they go out and seek it. They are innovative and take initiative.

> They're really, really, really smart people, and they need to be stimulated. And so I think people in the field, they get bored. And what they do with that boredom sort of determines greatness or not. Some people turn it into new opportunities, they go new directions, they create things, they find things, and other people don't.

How they address boredom may be one factor that sets master genetic counselors apart from others. Inspired by science and learning, and with a personal drive to improve, master genetic counselors are driven to go beyond the status quo, which, they acknowledge can sometimes be positive, and other times negative. As one individual said, they may not be settled by anything.

> I think a lot of it is wrapped up with personal drive, a drive to improve. I think it's that drive to not accept things as the status quo, not to be content. Maybe it's more of a negative attribute than a positive one, that drive to keep moving forward and growing. I think it also connects with an innate curiosity and a need to keep improving. And I think that can be viewed as both a positive and a negative.

> I wonder, in a way, if a component of "completion" might be counter-productive to being a great genetic counselor.

Another participant described a differentiating factor in that master genetic counselors are people who grow throughout their careers.

> They're always on the brink either of self-discovery or new strategies with clients or innovation and creativity.

> I've had a lot of opportunity to learn a lot more than the genetics of the job. I think that that keeps you interested.

> It's our job, if you're going to be really a master genetic counselor, you have to keep it fresh, and however you do that --either its through clinical research, or though writing about your profession, or something. Or being involved in a professional society, the National Society of Genetic Counselors, something.

How they go about implementing their need for freshness varies from master genetic counselor to master genetic counselor. Some seek out more "effective and efficient" methods in the way they work, others move toward "doing research and collecting evidence for the things that we strive to do." For several, innovation means forming a new, re-evaluative perspective about the field itself.

> I think just looking at the current processes that are standard in genetic counseling, so many things we just do because that's the way we were taught to do it in school. Think about, 'OK, is this really the most effective way that we could be doing this?' Was this effective 10 years ago? Maybe, but the landscape has changed or health care has changed, and now there's a more effective way?

> One of the things that separates the master counselors from the other counselors is the master counselors *are* the ones that are driving the field, lecturing, writing, and doing original research, and that's how the profession grows.

> Having some passion, some willing to get engaged in some aspect of the field. Whether that's in the lab, being very invested in figuring out how we're going to bring new testing technology and make that accessible to patients and in clinic, or really caring a lot about who these people are and what their stories are.

Category 6. Self-Awareness (*n=8*).

The participants demonstrated an exquisite sense of self-awareness. They discussed the implications for self-awareness in terms of awareness of biases, values, ethics, and interpersonal interactions.

> I think people who are excellent clinicians have a very good idea of who they are and the interaction that has in a genetic counseling session.

> Well, probably one of the highest priorities is self-awareness. Having a superior [self] understanding—not just oh yes, I understand what I bring to genetic counseling because I have three kids and blah, blah, blah—but a much more in-depth sort of therapeutic understanding of who we are, how we were raised, what our biases and values and beliefs are and how that imposes and informs our work and can be barriers.

> I think we all have caretaker personalities. I don't think I've ever met a genetic counselor who wasn't a caretaker personality. I think sometimes that's to our

detriment. I think that's one of those things that you have to be able to stand back and assess how that helps or hurts your counseling skills.

I realize you're really talking about values here, not skills.

I have to pull back sometimes, in terms of when is [my curiosity] relevant-- when is this just vicarious and when is it useful.

Category 7. Additional Characteristics (*n=9*).

Participants often mentioned other characteristics they regard as characteristic of master genetic counselors. They are caring, gentle, empathetic and compassionate.

Compassion. I think I'm patient with people, situations, and co-workers.

Participants viewed master genetic counselors as creative, adaptive, and flexible.

Flexibility is key.

I think [what prevents some people from becoming master genetic counselors] is the inability to think outside the box and see that larger picture and the inability to adapt or reframe what genetic counseling is, keeping up with where medicine is going.

And what I learned is that for some family units, what works for others, doesn't work for some. Being aware and being able to be flexible.

Flexibility in both working with patients and colleagues.

I think you need to be independent, but you also need to be able to work with lots and lots of different types of people. And you need to be adaptable.

Being able to try things, and if they don't work, have a really quick new plan, or new way to go about things.

A few participants mentioned a need for control.

We're all control freaks, which is, I'm sure, a very consistent trait amongst all genetic counselors.

A lot of times people say genetic counselors are really detail-oriented; they don't tend to be as much big picture people.

> Being obsessive and all the rest of it, which I think is a very important trait of all genetic counselors, maybe not limited to master counselors.

> I think I'm organized and thorough.

> We're all very "OCD" like.

A few participants mentioned the importance of master genetic counselors maintaining ethical and professional standards. Others mentioned having a sense of humor that they use in their work. Some participants view master genetic counselors (including themselves) as humble in their perspectives of themselves and in their work. They are aware of and acknowledge limitations, including limitation on the impact they can have on clients. They make and admit to mistakes, and easily acknowledge how much they do not know.

> I just don't feel like I'm very profound.

> I don't know that I'm any more 'master' than anyone else.

> I'm not the best. I mean, I know I'm not the best.

> I think that that's what good genetic counselors understand. That it is a very humbling job. And it's also why good genetic counselors stay in the field... I think good genetic counselors have the ability to be humble. The ability to deal with being humble…You have a job to do, and how do you back your ego out of that.

One genetic counselor reflected on those she considers to be master genetic counselors.

> "When I think of the counselors I really admire, they're nationally recognized for their expertise. And you know what? Every time I've ever called them, they answer their own phone…by doing that, by sharing what they have and what they know; it in no way diminishes them. It's like excellence begets excellence."

Domain 2: Developmental Influences

This domain emerged from participants talking about the influences on their developmental paths. Questions leading to these responses included those about attitudes, values and traits of master genetic counselors and what inspires them as genetic counselors.

Category 1. The Influence of Family of Origin (*n=7*)

Questions about attitudes, values and traits prompted participants to comment about influences of growing up in their family of origin, family values, and valuing people in general. These values also emerged in response to a question about how the person they are impacts the counseling they do. The genetic counselors talked about the impact of their upbringing on how they approach their job. Some noted growing up in families with a strong sense of caring about others and the people they interacted with, and a value of providing a sense of community and to do good for their community. Others noted being taught that all people have value. Beyond philosophies of life, some talked about parental influence as role models, pride in vocation, and value of intellectual curiosity. One individual talked about innate intellectual curiosity she believes she inherited from her father, and another described a caring role model in her mother. Two genetic counselors remarked on the effect siblings have had on them.

Others talked about other traits that were—or were not—nurtured in their family setting. Clearly, some of the participants regarded family of origin as having had an effect that is visible today.

> Growing up in a family where there was a drive to do good for the community and be good people**.** I don't know if my parents had grown up in a different time

> or place, if that would have been as strong a drive. But it was a very important aspect of my growing up
>
> There are only a couple of things that can't be taken away from you. One is your education and one is your ability to be a good person regardless of your circumstances and to do good. It's hard for me to say if it would have been exactly the same [without having learned these values in her family].
>
> I think, ahh, my mother; my mother doesn't know the meaning of the word "stranger." And I think that that got taught to us. Mom tells me of experiences even when I three and four-- we did a lot of traveling, and she says, "You know that 'no fear' slogan? That was you!" And that was actually all of us. We also grew up in another time and place. My mother never had to worry about us being kidnapped. So there was a generational issue.
>
> I think I was raised with respect for persons. Neither one of my parents went to college. And, I was always taught that human beings--all human beings--have value, and that some human beings do not have more value than other human beings. So I think that does impact how I approach this job.
>
> [The influence of family] was very much true for me. I have a [family member] with [a genetic condition] and I was going to be a special ed teacher and got side tracked when I found out about genetic counseling.
>
> I've had genetic counseling students, or people who think they could be genetic counselors, say to me, 'Oh, I could never handle that. I can't handle kids that are suffering,' or that kind of thing. And to me, that, I grew into this. I was brought up in this terribly neurotic family, based on guilt, and I think it was the perfect testing ground!

Other genetic counselors talked about the influence of family reinforcement of traits they express in their work today.

> I was raised to be a very intellectually curious person. My father was very intellectually curious. The dinner time conversations at my house were probably not very common dinnertime conversation. And his intellectual curiosity is probably something that I inherited.

Sometimes the traits emphasized by different genetic counselors' families were quite opposite. For instance one noted:

> I was raised to be sort of second to no one.

While another said:

I was brought up to be a people pleaser.

One participant described the impact of being told she could not do something, while another discussed a family message that all work was honorable and should be done with pride.

> When I was a kid, when I wanted to do something that my folks didn't think I should do, they would always give me these lines about how with experience you'll know better than - stuff like that. So I'm always hesitant to use any phrase that says that.

> When I was growing up there was always the message if you're going to be a ditch digger, be a ditch digger with pride. Which was that all work is honorable… I think I have a very good work ethic… you do the best job you can do no matter what.

> My mom would have been a nurse if she'd had a choice, but she didn't have a choice to become educated in that way. But she took care of everybody in the family... to my dad who ended up having dementia, and to her mom. So we saw that she was our role model in taking care of other people. So it was a great training ground for that.

Three genetic counselors talked about current influences from family, two centering on having children, and the third in gaining wisdom from a respected sibling.

> I have learned from [parenting a challenging child] that sometimes you can only do what you can do.

> I learned from my brother: He's a [religious person]… It would just kill me [to stand up there giving a sermon while [it appears that] nobody's listening. And you know what he said to me? He said, "How do you know when people are listening?" That was wisdom.

Category 2. "Infectious Excitement": The Impact of Mentoring (*n=10*)

Mentors were very important to these master genetic counselors. Mentors provided support and feedback, and importantly, offered ways for the developing master genetic counselors to engage in the field. The participants credited mentors with helping

them to identify their strengths and encouraging – even "prodding" – them to develop those strengths as a way of finding their niche. Mentors provided opportunities and fostered enthusiasm, often by sharing of themselves in ways in which the developing master genetic counselors identified.

> I remember some people that I interacted with years ago, how much it influenced me when they would get excited about learning! A few people earlier in my career who would say, "Oh this is so cool!" or "I just had the most interesting interaction with that family and they shared this that or the other thing with me and it was so unexpected!" I think that excitement was kind of infectious.
>
> I've been sort of prodded. People recognize you have something to contribute professionally, saying, "Hey, you're sort of an engaging speaker!" So part of being a master is having some mentors, in a sense, or some people who kind of know that's how you get to be really good.
>
> I saw that [her mentor's encouragement] aligned with what I wanted to get out of my career.
>
> There are many things that one learns through the great-teacher experience.

Now, as their mentors once influenced them by sharing their passion and encouraging involvement, these master genetic counselors were passing on what their mentors gave them to the next generation of genetic counselors. As respected elders or mentors, they were providing support, recognition, positive reinforcement and opportunities for experience.

> So [my mentors] get you to come talk at their groups, and get you to come meet their patients, and they get you to do things like they did because they know that's how you really, really get into it. Which is now how I kind of coach some of my students when they get farther along in their rotations: The way you're going to get better is to get out there and get engaged in this.
>
> And I think that the families with whom I interact, and the students whom I mentor know that I'm *genuine* about trying to help them achieve their goals, or their aspirations.

In addition to viewing mentoring as promoting their mentees' development, a few participants described their role of mentor as an integral part of both their own development and their legacy. They viewed learning as bi-directional.

> You know you don't just learn from people who are older and wiser than you. I learn so much from my students.
>
> I think from teaching, and then learning from students is another huge source education.

One participant described a desire to include students in a consultation group despite opposition from others.

> "It's ignoring how much you can learn from people who are younger, which is one of the biggest reasons, I think you get ossified, if you're not learning from younger people.

Category 3. Influence and Inspiration from Colleagues (*n=13*)

One of the most robust findings arose from responses to questions about what inspires participants as a genetic counselor.

The participants highly valued their relationships with colleagues. Many expressed appreciation and respect both for fellow genetic counselors and for members of their health care teams. They also valued the support they receive from colleagues. The counselors enjoyed cross disciplinary learning from colleagues. They often found inspiration in their co-workers, feeling humbled by the skills and passion they see in them. As one individual commented, "My co-workers are all top notch people."

Two counselors mentioned peer support or peer supervision.

We do a lot of self/peer support, peer supervision.

From my genetic counseling colleagues it's probably more of discussing cases.

The master genetic counselors valued teamwork and equality within working relationships.

> You know I think you work in a health team enough and when everybody is really working for these patients, you want to do the same. I work with a great group of genetic counselors who I know feel the same sort of passion as I do for this job. I think that's very inspirational.
>
> Working for a larger university center where you're exposed to physicians and other genetic counselors who are all quite different, with different strengths, we learn from each other. That's a benefit for me.
>
> I think people use the term 'bedside manner'. I was in our intensive care nursery once when the director of the nursery got paged off the tennis courts. He came in in a disgusting tennis outfit with sweat dripping down him, with a tennis racquet—literally with a tennis racket in his hand—and sat down with this family … And there was just this… you know, he was no longer on the tennis court, the only concern he had in the world was their child and what we were doing for that child.
>
> Currently I work in [specialty], and I fortunately have a very wonderful supervising physician who basically wants me to understand everything about [condition].

Consultation, support and affirmation from colleagues were important to several counselors.

> I have a good network of people, if I feel I need to run something past them; I'm really comfortable doing that.
>
> You feel good when a colleague or a referring doc calls you specifically and says, "Hey, my patient thought you were really good." We all have our insecurities, and it's nice to get sort of an outside approval, too.
>
> I am so fortunate I work with a [professional from another field]. She's great. I like to sit next to her at lunch because then I feel better afterwards.
>
> I also am very fortunate to work with a group of physicians who have great respect for genetic counselors and I've certainly worked at other places where that was not the case. And you do start second guessing yourself, I think, when that's who you're working with.

On the flip-side, three genetic counselors talked about instances in which they did not feel a sense of teamwork.

> There are a couple of doctors with whom I just really don't work because that's their M.O. They're not going to be a team member. If you don't see me as an equal part of the team, then it's not going to be a working relationship.
>
> I work in a setting with other counselors and physicians. Primarily it's the physicians that take patience.

Three genetic counselors mentioned wanting more opportunities for peer support/supervision. Interestingly, one had the most years of experience and one had the least years of experience among this sample of master genetic counselors.

> I think that we're missing that in our field in North America, that peer supervision.
>
> I want a place where I can develop my skills. We talked about trying to get supervision.
>
> I'm also looking for opportunities to learn from other genetic counselors.

Domain 3: Master Genetic Counselor Development

This domain includes participants' comments on their own developmental process as well as that they see in students whom they see as potential master genetic counselors. They acknowledged the profound importance of the underlying "knowledge piece", and acknowledged a detail-orientation necessary to understand and communicate it. The participants described a gradual learning process of understanding which pieces of information are important and of gradually integrating those into their interaction with patients.

So, in summary they described starting with personal characteristics, adding some salient influences, gaining the requisite knowledge, and building on it, by learning how to integrate the salient information with human interaction. And all the while, being humble in realizing they will never see it all.

Category 1. A Developmental Process (*n=15*)

In response to a question inquiring about their perception of the length of time it might take to become a master genetic counselor, *all* of the master genetic counselors described a process of development.

A few of the master genetic counselors thought some genetic counselors may be "naturals" at the work, but they see those as they exceptions. However, the master genetic counselors noted that the *potential* for development into a master genetic counselor may identifiable early on. Many of the master genetic counselors noted that they see particular students or early career genetic counselors whom who they expect will become masters.

> I have seen people that are naturals. Just like naturals in different sports. They come out of the box and they just have a way of talking to people, they're comfortable in their own skin, they know what they can and cannot do. They're naturals, and most people are not.

> We've hired [many] genetic counselors on and off since I've been here. We've hired a couple that have been out for 5 or 6 years, and I have to say I certainly wouldn't look at those individuals and say, yeah, they are master genetic counselors. On the other hand, we have a genetic counselor here who has only been out for 3 years, and think she's very much on her way to becoming great.

> There's a graduate of our program who's only been working for less than a year, who I think is masterful. Perhaps she's not yet a master genetic counselor, because she doesn't have a wealth of experience yet, but the work she's doing already at this level is mind blowing. It's just unbelievable. She came into the program as an incredibly intuitive, intelligent, innovative thinker.

Category 2. Experience Required (*n=10*)

Several genetic counselors, however, said that becoming a master genetic counselor requires experience that builds on personality traits, and that takes time. As one counselor noted, "experience really does build you over time."

> I think you could certainly be a new graduate and be a very good genetic counselor, but I think there's a tremendous amount of room for growth-- for professional and personal growth, and I think those both really, influence the work that we do.
>
> Your personality is probably compatible with what you're wanting to do. But being a nice person, being a good person doesn't necessarily make you a good counselor.
>
> I think you have to have certain traits going in and I think you have to learn how to harness and develop those traits.
>
> But then I see some of the very new genetic counselors that don't have a lot of the patient experience under their belt, but have many of these skills--which again it must be somewhat innate and somewhat a part of their training--that allow them to really [excel].

While they contend that developing into a master genetic counselor takes time and experience, what length that might be is particularly difficult to quantify, and varies from genetic counselor to genetic counselor.

> I'm not of the school that I would say that you have to have been in the field for 20 years, but I don't think it's possible to be one right out of school.
>
> I think [experience is necessary]. What I don't know is that there's any magic number of years of experience. For some people it may be a few years, for others it may be many years.
>
> I think it depends on how you define "years." I think it does take some time, but I don't think there's an exact timeline. I think some of these skills are going to be innate to a genetic counselor when they enter the field. But I don't know if you can put a time line of sorts on this elusive "master" genetic counselor thing.
>
> Well, I guess, if I consider myself a master genetic counselor, it's certainly taken me years to achieve that. I don't think I stepped into it as a master. Boy, I'd have a hard time saying somebody is a master with less than 10 years of counseling. They need to get a broad scope of experience; it probably takes some of us more than others.

> Of course just the knowledge base, the clinical knowledge base takes forever because there's a million little footnotes that you've got to get, and learning those footnotes and which are important and integrating them into your interaction with the patients takes a lot of time.
>
> [Master genetic counselors] need some years of experience, but do they need 40 years, 30 years, I don't think so. I think it took me a whole lot of years. And it won't take [particular person she has in mind] that long.

Category 3. Quality of Experience Trumps Quantity (*n=13*)

More important than length of time in practice, the master genetic counselors see the *quality* of experience as more influential in developing a master genetic counselor than the *quantity* of experience. The experience they see as foundational in becoming an excellent genetic counselor can come from a variety of sources. Several suggested that development of master genetic counselors depends on opportunities to be creative and to push themselves beyond their anticipated limits. Others suggested that "life knocks" which enrich a person and add depth to their personality can play a role. Particularly experiences which give insight into other people's worlds and losses can be especially salient in helping to develop the empathy necessary to be a master genetic counselor.

> There's a certain amount of life experience that creates perspective for you. If you don't have them, I don't know how you would have the vaguest notion about the implications of the things you're trying to have a conversation about.
>
> I think that anything that we experience that gives us insight into other people's worlds, and people's losses can help us become more effective genetic counselors; can help us to develop empathy.
>
> I can image some people who enter the field later in life after having lived a variety of experience, maybe lived overseas, worked with refuges, had another career, you know, kind of taken some of life's knocks. And all of these things can enrich a person and give their personality more depth which can contribute in an important way to someone's effectiveness in genetic counseling.

> I do think that garnering a lot of life experience—by that I mean your own life experience as well your professional experience–contributes to the people who we think of as being great, but I don't think it's a requirement.

A couple of the master genetic counselors noted the importance of learning to apply life experience to the genetic counseling context.

> I think a master genetic counselor must be somewhat seasoned, even someone coming into the field with a lot of life experience. Although she might start at a higher level-- higher in quotes--she is still lacking the experience of applying that life experience to genetic situations and clients.
>
> So you either have people who don't come in with a lot of life experience and they have to build that, or you have people who come in with it but they still they have to take the time to figure out how their experience applies.
>
> So I think its both counseling experience and life experience that are an integral part of this.

Category 4. Learning from the Patients (*n=11*)

Most of the master genetic counselors agreed, however, that the most significant impact of experience is learning from the families they worked with. Through work with their families, the master genetic counselors expanded their skills and techniques, and learned over time what works and what doesn't, sometimes in humbling ways.

> But if I think back to my upon my career, I think that I've learned so much from the families with whom I've interacted.
>
> Certainly for me, I think, experience is very important. I'm fond of saying, "God help my first 60 patients." I think that you have to be humbled a few times, at least, in order to really make that transition from the classroom to the counseling room. I don't think anybody can do this without making some mistakes. And of course you've got to have the ability to learn from your mistakes. So for me that was important.
>
> I do think there's something to be said about clinical experience informing your clinical judgment.

> There's just no substitute for doing it over and over.

> Well, certainly I try to learn from my patients and recognize that even after 27 years they still have something to teach me.

They gained intuitiveness about what patients might be thinking or feeling, allowing for deeper empathy.

> So a lot of that assessment piece does come with a bit of time and knowing, and sometimes knowing the questions to ask based on experience. Because you know [what] the patient's thinking. And you can't teach that in school. I mean, a bit, through clinical rotations, but sometimes just getting out there, seeing how these really life changing events affect people; you can only do that with time and experience.

> I've worked with [disease] families for almost a decade now and I just sort of have a sense of what the issues are that we need to discuss. I've seen what happens in families with the diagnosis and you just can't learn that in a classroom or in a school.

> [With experience] you've got thousands of interactions you've gone through. And it's like, well, I've tried this with that kind of person, and it just didn't work. So you sort of gauge, try. [You] basically have this body of experience you can go back to and then you get good at figuring out that in the beginning if you do x, y. and z, you can sort of adapt a little bit to that style and try it out. And sometimes you're desperately wrong, but…

And they've struggled with challenges:

> I think you need to find yourself in situation where either things go very well or they go very poorly and find a way to navigate through that. That just doesn't happen the day you leave the training program.

> But I think that so much of what we learn happens after graduate school in the real world. I don't think it's possible to be a master genetic counselor without having been on your own in a job and given the opportunity to be creative and see what it's like in the real world and then sort of push yourself beyond the limits of your job descriptions

> …or having a way to do it and then doing that dozens or hundreds of times, then you can start to go, "Ahh! I can create this differently. I can depart from this more easily."

Category 5. Shift of Focus from Information to People (*n=2*)

A couple of master genetic counselors described a shift during their development in which their measure of their career competency changed from one of knowledge of facts, to being able to “ be” with the patient as patient as a human being. One master genetic counselor referred to this as becoming more than “an information vessel”. One described the information as becoming “hard-wired,” or “integrated and automatic”. This in turn, allowed for more engagements and focus on people as individuals. So, integration of information seemed to allow for development of attunement with clients for these master genetic counselors.

> In the beginning you sort of measure your competency by how well you can gather together a few facts and then sort of get the job done in a sense.
>
> I think when a genetic counselor first starts out, your focus becomes more “do I know all the information and will I be able to present it factually, correctly”. And as you develop as a genetic counselor that becomes hardwired. And that allows a transition so you’re able to relax more about that part and focus more on people as individuals and tune in more to what’s going on with them.
>
> Early on I thought [competence] was preparation and information and now it’s more intrinsic. Previously it would have been, well, ok, I’ve learn everything I can learn about this, I’m all up to date on it. I sort of know what 8 or 10 questions to ask them. Whereas now, I can just sit there and sort of anticipate what are going to be important issues. Just sort of being there; I can be there more as a human being, and less as sort of an information vessel.

Domain 4: The Person of the Master Genetic Counselor

Grounded in solid genetic knowledge, self-awareness, confidence and reflective practice, master genetic counselors develop an effective counseling style that builds on and fits with their individual personality and strengths. Master genetic counselors are genuine and authentic, bringing their real selves into their counseling work. This theme reflects responses to the question of how the person they are affects the genetic

counseling they do. One participant described this as "reaching into my 'self' and growing skills--just trying to reach things that are part of the original equipment." *Who* they are becomes inextricably integrated into *how* they practice.

Category 1. Their Personality *is* Their Style (*n=14*)

Master genetic counselors' individual counseling styles are grounded in their individual personalities. Because master genetic counselors' approach flows from who they are as individuals, many participants expressed a belief that there are many different styles among exemplary genetic counselors. A key point they described is being authentic and genuine in one's professional relationships. Many described an overlap or integration of their personal and professional selves. Interestingly, participants chose their words carefully in discussing this topic, seeming to not want to elevate one particular style or professional identity as "the" way of being a master genetic counselor.

> It's ok to have a personality and be a genetic counselor. It's OK to really talk to people like a regular human being.
>
> Your personality is your style. The great philosopher and baseball manager Sparky Anderson used to say, "You is what you is, and you ain't what you ain't." And that's pretty much it. Your personality is coming out in the genetic counseling session, and mine does. I have a big ole personality and there's no doubt it comes through, and that's probably what makes me a good or a bad counselor to different people.

Participants discussed in depth, and with considerable awareness, significant overlap between their personal characteristics and their professional identity development. Most considered the salient characteristics as having been true of them their entire life.

> I tend to be really calm, that is just the example that I would use. People often say about me that I have a way of just being calm, and how I approach things, that tends to calm patients down. I think that's part of how I operate in any realm.
>
> I really think the person that I am is the person that I am as a genetic counselor. Maybe sometimes to a fault. You know, I'm pretty conversational and I'm pretty open and so I think I have fairly good people instincts and can relate well to many different types of people. I think that's something that's been true of me all my life.
>
> I'm also a "toucher", and I've been a toucher [all my life]. I can appreciate there are a lot of people who are not touchers, and it's not like when I meet people I hug them instead of shake their hand. But I also do find myself touching shoulders and touching knees, and I think that that part does generate that closeness and that understanding. It's also my style.
>
> There are so many aspects of who I am that affect what I do. I'm assertive. I have an outgoing personality and so, compared to some of my peers, I'm sort of way out there. Rather than sit and be silent—which can be a perfectly appropriate counseling technique, especially with somebody who's grieving—is not something that I do very often…I'm extremely high-level interactive and very dynamic. I'm not afraid of making mistakes. I think because I have high expectations of myself, I have high expectations of my patients. I mean the list goes on and on and on! Every aspect of myself is reflected in my work!

Category 2. Use of Self: Genuine, Authentic, and "Comfortable in their Own Skin" (*n=9*)

Master genetic counselors interact at a human-to-human level. No longer feeling a need to hide behind a persona or facts and figures, many of the participants found genuineness and authenticity to profoundly affect relationships with patients. Master genetic counselors' "use of self" helps develop rapport, encourages a strong genetic counselor/patient alliance, facilitates communication, and provides a safe space for clients to open up emotionally. Use of self includes authenticity in their emotional reactions to patients in sessions. In terms of the genetic counseling process, participants were astutely aware of how their personality works in session.

> I found the more I am who I am, the more I think I sort of engage people. So I've moved away from trying to ask maybe typical counseling questions which are very uncomfortable for me and just didn't feel like the way I would engage someone. You know, in my regular life I don't utter the phrase, "and how do you feel about that" very often. I try to be fairly unstructured and informal and that would probably be my preference. Just to sit down and instead of saying I'm going to ask about this and this and this, I'll say, "Tell me about your family." You know, and tell me a story, informality, which is nice because it's how I am, and I feel like the sessions kind of go better because that's how I am in real life.

> I suspect that my years of experience, and maybe mellowing as I grew older, allowed me to be more open in sharing [my personality] and making them feel safe when they come in to a genetic counseling appointment. Families know that I really am genuine about wanting to help them. And I think that that really helps in establishing rapport and that's probably more an inherent trait than something that I was able to learn.

> Well, I tend to be warm and empathic and eager to please, eager to be liked, all of those. I have a very strong nurturing, [parental] instinct, and so I think all of those features allow me to be warm and friendly and I get a lot of people confiding in me. They'll say, "I don't know why I'm telling you all this!" But it's just that sort of you know, I'm safe. I'm not someone who's going to judge or tell them, or look at my watch or anything. So I think people do feel that. And also I am a people person, and so that ability to figure out pretty quickly how to "be" and how to help. And the word choices to use.

> After you've done [genetic counseling] for a while, you get good at it, and you're not really afraid of silence in a session, and you're not really afraid if people start crying or even if you cry yourself. OK, it happens. It may not be as professional as you want it to be, but it happens. It's OK. I think genetic counselors sometimes don't feel like sharing their personalities, being authentic. If you pull out your little diagrams and all you want to do is point to things, you're just hiding behind all that science. That's really not what it's all about.

> One of my things is I get emotional, Beaver lost his baseball cap? I'm in tears! You know. I can't hide that when I'm working with people. When I feel things, I feel things strongly and visibly. And so it's bringing those features of ourselves to the front and making them strengths, rather than trying to make myself rigid: "I must never get tears in my eyes because that's unprofessional." No, it's like, that's going to happen to me sometimes.

Some participants remarked on an in-session awareness of how they use who they are in the genetic counseling relationship. Several described monitoring in-the-moment

genetic counselor/patient interactional dynamics, such as modulating themselves for the patients' benefit, and attention to boundaries and professional competencies.

Some participants described a positive feedback loop in which being authentic engages patients, which then reinforces the master genetic counselors' intention toward authenticity.

> I realize, that I'm sort of a goofball and I sort of act like that, and it works for some people, doesn't work for others. I know when to turn it off and on, or up and down. I think I found the more I can just sort of engage people as the person I am, the better I feel about how I do this. So I think letting some of my personality bleed into it has helped me feel a lot more comfortable with how I do it. In the delivery of genetic information, also, I use humor a lot, and I don't know how better to operationalize what I'm doing, but I do feel I'm using my "self."
>
> I guess I would say I'm not extremely comfortable venturing way too far into psychosocial issues, and maybe that's where that discomfort came from [in a particular difficult case]. I sort of see myself as a scientist first, who can be somewhat empathetic and nice and understanding of people, and I think where I get uncomfortable in my skin, so to speak, is where I'm venturing too far beyond my comfort zone in terms of psychosocial skills. And recognizing, that ok, this is out of my league and I can either ask questions and get me into places I don't want to be right now, or I can say, You know what? I've got colleagues and clinical psychologists who, if I'm uncomfortable with this, I just need to send them to them. So I think trying to be a super-duper psychosocial counselor probably was the point where I got uncomfortable in my skin and realized, I'm trying to be someone I'm not. How can I be who I am and be helpful to people? And that was probably a transition point.

Category 3. Sense of Professional Self Matures Over Time (*n=6*)

Authenticity and use of self is a developmental process for master genetic counselors. Master genetic counselors' sense of authenticity develops over time and follows from their individuation from teachers and mentors.

> In the beginning I think I felt I had to be [name of teacher]. I think we all felt we had to be [our teachers] essentially. And I can see that in students. I can see

> they're trying to be someone they're not necessarily. My growth occurred in trying not to be who I wasn't. That's always been who I am, and probably the clinical transition was being comfortable enough in my skill set and my knowledge to just be who I was. Trying to be someone who I wasn't perhaps wasn't the best way to be helpful.
>
> I think it's taken time. You have to get comfortable in your own skin. You know you're really uncomfortable when you're a teenager, and you're a little more comfortable in your twenties. When you get wrinkly you get real comfortable [laughs].

Master genetic counselors' authentic use of self becomes more refined over time and plays out in interaction with colleagues as well as with patients.

> I've noticed throughout my career trajectory I've been using my personality more and more. I think it's hard to be more concrete about it, but I do feel at a gut level that I really use my personality to a great extent.
>
> I have a sense of humor that sometimes surprises my student colleagues and my professional colleagues. Some of it's an age. I'm in a place now professionally, where I sit at the table with a fair number of relatively senior and higher level clinicians and policy makers, and I don't have any problems saying, " Oh, [Name] define the royal 'we," because if you can't put a name on that then ..?" Like this morning at [a meeting], I don't know that I was "the voice of reason," but I said, "This isn't going to work unless you do this and this and this." I don't know how it turns out that I'm the only one who feels like in public I can say that.
>
> As we grow older, many of us, maybe not all of us, many of us mellow a little bit. I suspect that I was more reactive when I was younger and I think now that I might pause more and think about things before reacting to them. I would suspect that in many parts of my life I was much more reactive.

Category 4. A Merging of Personal and Professional Selves. (*n=5*)

A few participants appeared to be quite compassionate and heartfelt in talking about the integration of their personal life values, philosophies, and worldview into their work. They expressed this integration as a concordance or merging or overlap between their personal self and their professional self.

> People don't get a fair deal in life. And I like to think that sometimes when people aren't getting a fair deal here, there are things that I do and say that make things a little easier for them, and a little better for them. That's kind of how I would like to be thought of in terms of how I live my life in general--that I'm a caring person who would want to see that in the world there really is some justice—that nobody's going to bed hungry, nobody's going to bed homeless, and all those other sorts of things. And I think that sort of overlays into how I feel about the people that I work with, both my colleagues and the families we see, in terms of trying to help them in the midst of a really crummy situation. I think since I was a young adult that's been something that's been real important to me.

> I think the things we value in ourselves, I think they glimmer through in our encounters with people… We can't hide who we are, even though we might want to. My personal values are loyalty, honesty, honesty with myself, honesty with others, those are important to me, and I think some of those things do carry through. I think [wanting to make a difference] is probably wider than just genetic counseling, I mean it's what I aspire to. Whether I achieve it is a whole other question.

Category 5. The Importance of Fit (*n=9*)

Participating master genetic counselors find a specialty, work environment and organizational culture that fit their personality and professional style. This theme often emerged in response to questions about how who they are affects the counseling they do and what they think stands out about themselves.

For one participant, a casual worksite is important.

> I'm really, really casual. I've always been casual. I did my graduate work in [a different state] and it became very clear to me that this was not going to be the environment in which I could work. Because it was too "professional" for me, you had to wear friggin' suits! I'm looking at my socks today and I'm just kind of laughing—they don't match! The good news is hardly anybody's going to look at my socks. But you know, there would be places in the country where you'd have to go home and change. Now that's not to say we don't have a dress code, dress neatly, but I am a very casual person, which I think quite frankly makes people feel comfortable.

Others talked about the fit of their personality with the particular type of patients they see.

> You can probably tell, I'm a very matter-of-fact person. I'm not a huge psychosocial genetic counselor, and so that's not really the part of my job that I enjoy [most]. It's important to know who you are and where you're going to excel. That may be a master skill also, determining where you best fit in and creating a niche for yourself there.

> I have the luxury of doing genetic counseling for [specialty]. And there's a huge bias in who comes to see me. It's a wonderful fit for me. Because the people who come to me, by and large, are interested in this. They want to know, which is so different from a [specialty] setting. So I think maybe part of what makes an excellent counselor is a good fit with your job. The only reason that I feel I'm good at this is because the right people are coming to see me.

Another enjoys a work environment that offers variety.

> I really enjoy the juxtaposition of doing a lot of research, especially on people who are affected with [disease]. I think that gives you a lot of insight in the collective way, as well as seeing patients, as well as teaching. I think that helps me keep it in perspective.

Domain 5: Reflective Practice and Self-Awareness

Category 1: Self-Reflection is Crucial, Dynamic, and Continuous (*n=11*)

When asked about characteristics that might differentiate a master genetic counselor other competent clinicians, 11 of the participants identified self-reflection as key. They commented that self-reflection encompasses more than just thinking about their work; it includes a willingness and openness to "critically analyze" their thoughts and/or behaviors in order to understand motives and to grow and improve. They view this effort to "self-evaluate" as a "constant".

> I also think that when you think about great genetic counselors, you think about people who really do self-reflection and who do [self-] assessment.

> I would think a characteristic that could distinguish [a master genetic counselor from a good genetic counselor] would be an interest in self-evaluation and then a pretty constant attempt at reflection.
>
> There's a willingness to really self-reflect and get input at a deeper level in order to really grow and improve.

Self-reflection is "an active process." It requires openness, honestly, and nondefensiveness.

> The ability to self-assess and to be critical of what one is doing, always--a reflective practice. It's more like an activity I guess, than a personal trait**.**
>
> There's openness to not only to exploring yourself, but also discussing yourself and your cases with other people; which may or may not involve formal supervision or just colleague interaction. And a willingness to be non defensive: honest and nondefensive.

Category 2. Self-Reflection Leads to Insight and Growth in Self, Practice, and Professional Development (*n=8*)

One master genetic counselor spoke of using self-reflection to avoid working on "auto-pilot" with routine clients. Another finds self-reflection effective when "self-doubt plays over and over" in her head. Another noted that reflecting specifically on her own developmental process helped her individuate from "being her teacher to being [herself]".

Others consistently use self-reflection to deepen their understanding of interactions and the process of their sessions. Self-reflection helps them let go of perfectionism while also learning from situations that did not go the way they would have liked.

> I think introspection is a very important part of being a good genetic counselor. Because we're not all good, every day, all the time. I think when you have a bad session, [it's important] to examine why it was bad.

> The first thing I ask myself when I[conclude] a case is what could I have done differently? What didn't I like about what happened in that case? It's just natural now for me. I don't even think about this consciously, but that's how you grow**.**

> In the evenings or after each clinic kind of going over in one's mind--processing the sessions--and trying to determine what was really going on. Did I miss anything? How did that go? How do I feel about that? Why do I feel the way I do about this particular patient? Is there anything there? And a willingness to be not defensive--or an *ability* to not be defensive.

> It's one thing to be able to reflect and [then] write about something. But when you're actually [in the midst of] counseling it's a lot harder [to self-reflect].

They strive to understand how who they are affects their interaction in session and in professional relationships.

> So I think learning balance, learning to be more mellow, learning to be not so high energy. I'm a morning person, and I'm actually starting to get pretty good about not being too perky at 7:30 in the morning! Everybody is still sucking down their coffee, and [says] "Don't smile at me until 10!"

> I wouldn't say that I have a gentle personality. But I know how to be gentle when I need to be.

It was clear from the details and depth of their conversations that much of their self-awareness comes from reflection and seeking internal understanding is a part of who they are. Two genetic counselors noted using psychotherapy as a process for self-reflection

> I've actually been in therapy myself.

> And frankly, I have sought counsel when I needed it**.**

Some master genetic counselors find themselves growing more introspective as they mature.

> I think that as I have gotten older, I have had more introspection. I think as I've gotten older I've been more able to examine my own motivations. I think it's very hard for younger people to really examine their motivations. I think that's

> something that does come with age and experience. And maybe more age than experience.
>
> [Master genetic counselors] are just incredibly self-aware and work on that as a continuing part of their professional development. Striving to understand ourselves because we are a dynamic process. And who I am and what I brought to the field 20 years ago doesn't remotely resemble what I bring and my biases today. So I think seeing that as an ongoing part of the work.

Category 3. Confidence (*n=8*)

The participating master genetic counselors expressed quiet confidence in themselves and in their abilities which they gained through experience, reflection, and sometimes a "persistent drive." Experiences build a sense of competence in themselves and in their work.

> As you get more experience you become more competent, and with greater competence comes greater confidence. It really is a nice feedback loop.

For some, self-confidence comes from within.

> I think some of [becoming a master genetic counselor] is developing self-confidence. When I left my training program, I wanted very badly to be a clinical genetic counselor; I had absolutely no self confidence that I could do this job. And for me where that had to come from was from within. So for me, I had to come to it round about, I had to do other things. I had to work in research for many years, and I kept coming back to "I want to do this, I really want to do genetic counseling…and when I did, I realized, "I wanted to do this because I'm good at it!" I don't' know where it comes from, but at some point, something has to come from within.

Others described gaining self-confidence through lived experiences.

> Living other experience can help make us better genetic counselors. Anything that is difficult can you make you stronger and also can affect your self-confidence and pride in yourself. Whenever one is feeling strong within one's self, one is in a better position to help other people, I think.
>
> I think that being in this field over 20 years allows you to feel more confident in the way that you do things.

Confidence affects session dynamics. When they feel confident, participant master genetic counselors felt more freedom to use their personalities, became more client-centered, and focused on emotional content of sessions.

> We are much more confident in our abilities. We can toss aside the notes, and go from the hip, because we know. We're not worried that we're going to forget something. We've had so much practice.
>
> At the end of the session, even if we've deviated completely from what we thought we would cover, we know that we can take a few minutes and fill in those pieces that are missing. So we're much more free to just use our personalities.
>
> I was comfortable to toss the plan, even if it came from my supervisor, my boss, and then just deal with the patient's major concerns.
>
> Perpetual learning and experience allows you to develop a comfort level with the materials and once you have a really firm knowledge then it's like that allows you to improve your emotional response reflexes.

In the same vein, participants expressed the importance of positive self-esteem. With strong self-esteem, they feel stimulated rather than threatened by students' and patients' questions, and are able to remain empathic rather than defensive with angry or upset patients.

> I've seen how self esteem can influence everything really. I've seen genetic counselors with not great self-esteem have much more difficulty in some of the roles that are involved in genetic counseling, like clinical supervision. They feel very threatened by the students' questions rather than stimulated. And I guess the same applies in clinical work. The more comfortable one is, the less likely one is to react defensively when a patient gets upset or gets angry, and the easier it is to remain empathetic.

Category 4: Realistic Expectations and Awareness of Their Limitations (*n=14*)

Participating master genetic counselors were aware and accepting of their limitations. They generally seem to know what they don't know. Interestingly, responses in this theme emerged from two different questions. One question asked participants to

identify distinguishing characteristic of master genetic counselors and, the other question, much further into the interviews, asked participants to talk about successful experiences with patients.

> [A distinguishing characteristic] is being able to say "I don't know," because sometimes, really, we don't know!
>
> I do know there's a lot that I don't know. I've discovered so much that I don't know, there must be plenty more!
>
> I think that's the [another] part of this, being honest and being able to say that, you know, at this age, there's still a lot I don't know.
>
> It's like the more I learn, the more I realize I don't know. And this is humbling.

Although they strive to do their best, master genetic counselors also recognize that each day will not necessarily bring their optimal performance. They have a realistic understanding that they personally may not be the best resource for a particular patient and that they will not make the difference they might want to make for every family. This understanding allows them to let go of control and perfectionism—to let go of their ego, as one participant put it, which may be a resiliency or balancing factor.

> Sometimes we're not the best resource for clients and the way we can help them most is get them to a better resource.
>
> My job is to do the best job I can, not necessarily to think about what was the best I've ever done. Maybe that's what makes a [master] genetic counselor, that sometimes it does go badly, and you just deal with that. And if you get too overly ego-invested in it, this job will kill you. Nobody is perfect. Nobody is going to fix everything.
>
> Because in some patients and families you're not going to make a difference and for some you really are. And so for the ones that you really can make a difference, it's really trying to make that difference. And not sitting back, but being more aggressive in making that difference.
>
> I think you have to be able to recognize that you're a little blip on the huge journey that most of the people that we're dealing with are going through, and

> keeping that in mind is really important. Not to say that you can't do something important during that blip, but keeping in mind that you are a blip the entire time.

> Many of those [successful cases] I have to admit just happen in the line of duty. They happen in the line of good patient care.

Master genetic counselors readily admit their mistakes to themselves and to others, and this behavior is soundly based in a belief that mistakes lead to growth. They are able to "own" mistakes, admit what they don't know, ask for help, and they do so in a "public way" in order to invite growth.

> That's not to say I'm always fully present or that I don't make mistakes.

> Realizing, "Gee, I've made a mistake" or being able to go to somebody else and say, "Help me see where I've made a mistake; help me here."

Category 5. Multi-cultural Awareness (*n=8*)

Although it was not specifically asked in interview questions, many participants introduced the topic of working in a multicultural world. They described working toward cross-cultural competence, and despite some frustrations, viewed working with diversity as an opportunity for growth. Those who discussed cultural issues demonstrated an awareness of their clients' life contexts as well as how those might differ from their own. The participants held a broad view of diversity, including in their discussions ethnicity, religious values, socioeconomics, language, cultural values and beliefs, and age (particularly working with adolescents).

The participating master genetic counselors commented that cross-cultural experiences taught them to challenge their own assumptions and more self-aware and

reflective about their feelings and responses. Noted one master genetic counselor participant, "You need to know your own prejudices."

> In my first job I was working with a lot of people who had very strong [religious] beliefs and values that were really different from mine and very unfamiliar. And I didn't know anything about them, so I had to figure out who these people were, what made them tick, what was important to them, how they could live with blaming themselves for 'having sinned and that's why they had an affected child', which happened a lot. So because of that, I couldn't make any assumptions. It was probably a really good way to start my career. Because I didn't know anything about anyone ahead of time, which is still true today.

Another participant discussed learning to more flexible and open to patients' and families' needs.

> We had an extended family and they were [ethnicity], and there were three individuals at risk for [disease]. They had decided to all come in together, and we're very discouraging of that. In our practice, it really wasn't the thing to do. Everyone has their own issues, and I didn't really want to get into an argument with them. [But]I learned a lot from this family. And what I learned is that for some family units, what works for others, doesn't work for some. Being aware, and being able to be flexible enough with what we want to accomplish to be there for our families and our patients [is key]. What works for one doesn't work for another. This family operates as a unit."

Another genetic counselor described working with an adolescent client and the client was "…sitting there, and she's texting…" At first offended because she felt ignored, the counselor changed her perspective after realizing, "You know, what? She was listening. She just wasn't going to let me know that!"

These master genetic counselors acknowledge that working cross culturally can challenge them, prompt emotional reactions, and require flexibility. Some expressed a need to balance value differences with content they considered essential to present in the sessions. This sometimes plays out in working with families from patriarchal cultures. In such cases, counselors sometimes experience frustration around cultural differences in

gender roles and decision-making styles. One counselor described the dilemma she sometimes experiences in working within a family's cultural values.

> [Patriarchal] populations where their cultures are astoundingly—for lack of a better way of phrasing it—disrespectful of women, and women have no role in any decision-making. We see these couples where you can't even address a question to the wife. Everything is through the husband. She doesn't speak. She defers. That makes me crazy. I can't help but think it's affecting what I'm doing and how I'm phrasing things and so on. Which, you know, begs the issue of, are there cultural—genetic counselors love to talk about this—are there cultural norms that we need to just back off and respect? Or should we not? I don't know. It's hard."
>
> "Well, we're sitting in these rooms knowing that whether or not this woman wants to have more children is really unrelated to whether or not she will, is unrelated to anything she thinks. That is pretty frustrating."
>
> So it's mostly inner city, or rural poor folks who come here for their care. And I just really have a hard time with the young teenagers, 17 years old, having their third kid with their third partner…I really have a hard time being—I really have to think about it before I walk into that room. I'm just not comfortable with it. I wouldn't say that it's necessarily a population that I don't do right by, but it's more that you just want to shake them and ask them [what they're thinking, where's your head? [said caringly] That's more the issue."

Some master genetic counselors modify their typical session style to address cultural differences, and most expressed considerable effort to understand their client from the client's perspective and worldview.

> It's much harder to get a connection with somebody when their use of language is so different. Even their body language, facial expressions are going to be different, so it's harder to read it. And so I started to just ask more direct questions rather than using this instinct, which I'm used to having and being good at, but recognizing that it's not going to be valid in all situations."
>
> This is [a large metropolitan area], so we do get a sophisticated group of people and so I can use all that genetic lingo, and yet we also get a fair number of blue collar workers and some people who are not at all comfortable and familiar with the terms. I definitely will choose my words differently.

Despite the challenges, participants seemed to express a richness and learning in working cross-culturally.

> I don't speak anything other than English, and so I miss being able to speak in their language but I really enjoy the very different perspective they bring to all of this.

Domain 6. A Collaborative and Interactive Relationship with Patients

This domain and the next one are significant in that they generated the greatest amount of participant input of all themes and were endorsed by all but one of the participating master genetic counselors. Further, the theme arose primarily from two questions: one inviting the master genetic counselors to talk about what distinguishes a "great" genetic counselors from a "good" genetic counselor, and another asking what they think is distinctive about their own practice. Therefore, it seems reasonable to infer that *process variables*, including facilitation of a strong working alliance and empathic understanding of clients' emotional states, play an important role in distinguishing exceptional genetic counselors.

The two questions also evoked "stories of practice" from the participants, sometimes quite lengthy stories, which they often told in detail and as narratives (see Emotional Impact). The narratives often carried an emotional overtone, or overlapping emotional overtones, including those of the genetic counselor as well as those of the patients. Some stories had positive outcomes and others did not. But regardless, in the telling, the master genetic counselors provided a look into *how* they practice.

Within the themes about their relationships with patients and empathic engagement, participants often turned from the third-person—talking *about* master

genetic counselors—to first person--talking about *themselves*. In so doing, what participating master genetic counselors identified as standing out about their practice is their relationships with patients and the empathic understanding and connection that underlies it.

According to participants, master genetic counselors are able to connect with individuals and families, sit with them in difficult moments, comprehensively track and attend to multiple layers within a session, including information, patients' readiness to hear information, eliciting emotions, assuring understanding in the session as well as understanding of the down-stream consequences of the decision. All the while they are communicating their emotional understanding to the patient.

Participating master genetic counselors are intentionally patient-centered. Even in situations of routine counseling they strive to view and understand the genetic counseling process and genetic-related issues from the patient's perspective. Participants talked of channeling this empathic attunement into in-session flexibility, a skill they see as setting "great" counselors apart from "good" ones. Consequently, they tailor sessions, avoid "information dumping" and are attuned to the needs of individual patients.

Category 1. Rapport is "Crucial" (*n=8*)

For the participating master genetic counselors, building rapport and providing a safe space where genetic counseling client can open up is "*crucial*" to exemplary genetic counseling.

> It's the most important thing, establishing rapport.
>
> I think [rapport] is a crucial part of it. If you're going to get past being a genetic information provider, then there has to be some rapport in order for people to be

> willing to raise issues that they would otherwise be unwilling to discuss with someone they met once or twice.
>
> And I think that's part of what people need to feel, that you are focused on them, this is what you want to be doing, need to be doing, care about, and that they and their child are very, very important to you.
>
> I think [one] thing is that people know I'm behind them. I'm there to support them and their choices and help them get what they want.
>
> I care about them, and they know I care about them.

Master genetic counselors facilitate development of a strong working alliance in several ways, beginning with their own assumptions. For example, participants expressed that they do not assume trust as a given.

> You're always on trial. [Patients] don't trust a stranger just because you're sitting in a health care office. It helps to be reminded that [trust] isn't just handed to you on a silver platter!

Master genetic counselors understand the importance of building trust and safety for a strong working relationship. Several participants talked about the importance of creating "a safe space" and putting clients at ease by letting them know "that you're in their corner."

Participants talked about accomplishing trust-building through client-centered measures such as valuing clients and their needs, being open to clients' perspectives and experiences, having a genuine interest in helping, and forming a reciprocal partnership that balances support with empowerment.

> I think the fact that I value the client, and what the client thinks comes across really early on in important ways and I try to maximize that.
>
> I think it's clear that I'm there to help patients. They get that sense that I'm on their side, and I'm not trying to sell them anything. I'm there to say, "Let's see what we can do to help you out one way or another here."

> I'm seeking to learn more from [patients] about their experience and their child's and their child's disorder. And they know that this is kind of a partnership, that we're learning from one another. I do try to present it as a partnership. And that I'm not going to take sole responsibility for their care. Nor are they left feeling isolated or that they have to carry the full burden on their own.

Category 2. Being Fully Present and Engaged Leads to Opening Up (*n=14*)

Master genetic counselors "really want to engage in a dialogue" as one participant put it. Several participants discussed rapport building in terms of "engagement" or "focus" on the client. Many participants described interacting with their clients on a personal, human level.

> I think it's the personal involvement. Leaving all the other activities when I'm in with a family. I may have a deadline or an appointment with somebody else waiting, or I know there's a problem I have to deal with, but it's pushing that to the very deep recesses of my brain, so that I'm fully present in the appointment.
>
> People don't feel rushed, even if they know that someone else is waiting for me. I'm really focused on them.
>
> And I think another thing is approaching each case as the most important thing that you could possibly be doing at that moment.

One participant noted a casual, conversational way of getting to know a patient.

> You get good at sort of reading within. You don't want to pigeon hole people, but students always ask "Why do you ask this question or that question at the beginning?" Like [asking a patient],"Hey, what do you do for a living?" It's not about what they do for a living. But by asking a few little questions, you sort of get a sense of people.

Master genetic counselors allow clients to open up by their listening, engagement and creation of a safe environment. Several participants noted that patients take advantage of this opportunity.

> When you start out meeting them, making sure they have a really comfortable and trusting place to be-- and you can set that environment. I think people know it and they can feel safer and they can share pieces. So when I ask a question rarely,

> rarely do I get a yes/no answer. And often, you know, I ask the question and then they get to talk for four or five minutes.
>
> [It's important that] they have a safe environment to ask [questions]. Because a lot of times they'll ask me things that are completely unrelated to the genetic counseling appointment, just because they feel like someone's really listening to them.
>
> I've have people stop and say, "Wow, that was my gut just hanging out." And I think it's that kind of stuff that reinforces that they understand that you're listening to them.

Category 3. Awareness of and Equalizing the Power Differential in the Counseling Relationship (*n=8*)

Master genetic counselors acknowledge their power in the relationship. Although they also acknowledge that the relationship is for the client and not their own sense of gratification, master genetic counselors do gain intrinsic reward from their work.

> I think that genetics is a very powerful thing. And I think that it's very easy to create a sort of unequal relationship with a client. In that you're the holder of the bag.
>
> A counseling relationship is essentially a one-way relationship. Although we derive great value from successfully working with clients, we shouldn't be structuring our interaction with clients for our own glory and success. That's a trap!

Many of the participants discussed working to equalize, or balance, the working relationship by honestly respecting and empowering patients, while also being aware of their own responsibilities in the session.

> Seymour Kessler, one of our leaders in our field, says to me "[Name], you don't let them be in charge. You're in charge. But in being in charge you allow the clients to have a clear voice." I said, "Ok, I'll say it that way!" [Laughs] He's right [that] you can't completely give up control to the client so you're not in charge of the session anymore, but I'm very flexible.

> The patients are smarter than I am because they've read it all on the internet before I have! "Yeah! Would you show that to me, that's interesting!" Sometimes, you know, they should charge me!

Participants see patient input in the same essential light as the master counselors' knowledge and experience. One noted, "Communication is all we're really trying to do here. We're just trying to communicate effectively."

> If you start the session with what you believe your agenda to be, that might be a pretty accurate assessment based on experience or what you read in their medical record. But, I think [it's essential], using some counseling skills, to let the patient really talk about what their expectations are, what their needs are. And then using what they're telling you to help and fill in what your knowledge and experience and training has taught you.

Category 4. The Pedigree: "The Ultimate Rapport Building Tool" (*n=7*)

Many participants talked about using the pedigree as a way to establish rapport and to get to know a family. The pedigree is an entry point they use to build a working relationship. They also use dialogue via the pedigree as a means of assessing a family's needs, "meeting families where they are" and negotiating a "way to relate." As one participant put it, "Hardly any family is saying everybody is fine."

> The pedigree is the ultimate in establishing rapport, because you can't really ask all these personal questions without establishing some rapport. Even if somebody doesn't want to answer them, at least you've got something to go on there. Because really, how are you going to know somebody? How do you know what they're bringing to the session?
>
> If you find out that they're divorced, or this is not the father of the kid, or they have a brother who's [developmentally delayed]. I mean, right away you have an entrée. Right away. And it's almost instantaneously. Because there is in every family something that you can tap into, some place that you can make a connection.

> I usually take the family history first, to try to get a sense through that more conversational interaction of perhaps educational level, emotional status, interaction with partner. Sort of sizing them up in a way.

Category 5. Deep Empathic Understanding (*n=14*)

Stemming from deep values of respect, master genetic counselors connect with patients in an empathic manner. One participant described "a drive to connect with people and to fully engage with our patients, to really understand them." Several noted that it is their empathy that stands out about their practice.

> Woody Allen says 95% of greatness is showing up every day! I think Woody didn't mean just physically showing up, but emotionally showing up, too.
>
> Make some connection, whether it be "This is very difficult for you" or even with our predictive [testing] patient, "Well OK, tell me a little bit about, what are you going to do with a negative result? What are you going to do with a positive result?" Very simple questions, but at least addressed some psychosocial issues.

Participants view master genetic counselors as highly emotionally intelligent, deeply caring, and possessing a sense of personal commitment or investment that they are able to communicate to their patients. They engage empathically.

> It's the ability to dig deep in the empathy well, and come up with it, even if on the surface the patient is being very difficult or noncompliant or resistant.
>
> [Exemplary genetic counselors have] a nuanced understanding and ability to use empathy…advanced empathy is necessary. Empathy is a really complicated concept. And it's not a set of behaviors that you can specify. It's like trying to put your hands on light or something.

Master genetic counselors are aware of what's going on emotionally for their patients. Participants connected this attuned engagement to advanced empathy and patient-centeredness. Rather than taking patients' communication at face value, master

genetic counselors listen for a meaning deeper than what a client is presenting at a surface level.

Many participants described their awareness of patients' emotions in sessions, and how they ascertain that. Several described using intuitive and perceptive skills, as well as life experience, to connect with clients' emotional pain.

> There's this internal dialogue: What else is going on here? What do I need to do to get to that place with them?

> I think after you've done this for a while and have yourself been in life experiences where there is tragedy, then you at least have a perspective about what that's all about. You're talking about having a sense of what it's like to face something, but also be open to how that might be affecting the patient or client. When you talk about talking about things they feel are threatening to them-- and being able to kind of maneuver around that, whatever it is that's hitting to the core of their being.

Participants also use immediacy and strategic questioning to check in with clients, confirm hunches, and provide an opening for emotional conversation.

> Well, you know, there's always the box of tissues, of course. And every now and then, if I can't read the client, I try to check in with them. "Am I overwhelming you?" or "How do you feel about that?" as corny as that is. Or "Gee, you look like you had a reaction there in your eyes, what were you thinking?"

The word "abandonment" came up several times, with participants expressing strong feelings of being there for patients.

> Obviously we deal with lots of very sad and difficult things, and my enthusiasm comes across as a willingness to stick with really hard things—to witness really hard things and not abandon people even when it would be easier and more tempting to do so.

> [In the past] patients were essentially abandoned. In the sense that they had a really tough diagnosis and then nobody talked to them.

As such, master genetic counselors address painful emotions. One participant identified skills in discussing difficult topics as a particular area of expertise for the field of genetic counseling itself. Participants seemed to see approaching difficult issues as a way of not abandoning their patients.

> I came to the [realization] that I could either go with my clients or not. I could either approach the most difficult topics with them or leave them to think about them themselves.
>
> I discovered that it was helpful to approach patients about topics like autopsy, or what do they think this baby is going to look like. Whether it's born or there's a pregnancy termination, what do they think? And I discovered that those kinds of discussions lead to really deep sessions.
>
> I had a patient this morning and their baby has a lot of [concerns]. They checked it on ultrasound and they're talking about proceeding with different testing. I was [thinking to myself], "But how are they doing?" They're asking all these detailed medical questions, while at the same time, there was kind of a sense or kind of an instinct that I had in there that they're avoiding some of the harder emotional pieces about this. I kind of stopped them and said, "You know, we're just talking a lot about so much difficult stuff, how are you doing with all of this?"

The participant also underscored her sense of pacing and timing of interventions as she continued:

> I don't think I could have asked that question earlier in the session because they needed some of the answers. But on the other hand, you know that's when the tears came and really not wanting to present this really strong front.

Participant noted they also ally with and voice fears patients may be experiencing.

> Clients may be either afraid to bring it up, or it's under their radar or they don't realize they're having feelings about it. But I think when we approach difficult topics with patients we give them the message that it's OK, it's not impossibly scary. We can walk there together and it is OK. We can talk about these things. It makes them less difficult just by letting some light in.

A couple of participants also acknowledged master genetic counselors' own emotional reactions in addressing difficult topics, indicating that even those who excel are not immune.

> I try to be relatively fearless in approaching difficulty topics. I say “relatively fearless” [because] nobody’s fearless in approaching difficult topics.
>
> And I try not to get defensive when they get angry with us.

A few participants expressed master genetic counselors’ belief in their own and in their patients’ abilities to solve problems and adjust to stressful situations, suggesting that this philosophy underlies their ability to address difficult topics. They further suggested that genetic counselors’ empathic engagement around difficult topics builds patient efficacy and empowerment.

> So values would be belief in both the client’s and the counselor’s ability to solve problems and adjust to stressful situations.
>
> Highly valuing the clients’ ability to take care of themselves, and having a very humble notion of what our role is in their ability to take care of themselves.

Domain 7. Nuanced Attunement to the Complexity and Multiple Levels of the Genetic Counseling *Process*

While building rapport and fully engaging with patients, master genetic counselors attend to the complex, multiple, interacting and *nonlinear* levels of genetic counseling within sessions. They do so *simultaneously*, and in a way that is nuanced for each session and each patient. Awareness of the multiple interacting levels of the session--including patient dynamics, genetic counselor dynamics, informational dynamics, and dynamics among all of those-- require master genetic counselors to be flexible. Many participants described their flexibility as a significant factor in the way they practice, and something that sets them apart from less professionally developed genetic counselors.

Category 1. Aware of Session Dynamics (*n=13*)

Many participants identified attunement to multiple layers within the session and pulling these layers together in a way that meets the clients' needs. One participant talked about the "nuance" necessary to understand complexity and "use it at the same time." Yet even the complexity itself is not static and is "ever changing."

> I think now I'm older and mellower and I would ponder a little bit more, and I think with patients. My brain would be trying to translate a little bit more about where their statement is coming or what their emotion or their body language is speaking to me beyond what is happening at one level.
>
> I think that something that happens with experience is that the whole time that they're talking, you're listening to them, but you're also kind of listening to what's beneath it or underneath it. And it may be how they say something, or what they don't say, or you know, there's so many different cues or threads that you see, and you have to decide which ones to follow.
>
> [An exemplary] genetic counselor really understands that what goes on in a counseling session has to be about the patient. You have to have good listening, not just good listening skills, but good skills at integrating what you hear into the session.

One master genetic counselor connected this type of listening to advanced empathy, and described it as "going underneath."

> Primary empathy is the feeling and the expression of that feeing to a client. Advanced empathy is then taking it the next step. So it might be something like having an intuition about what the client's really feeling, something that's not being expressed. I always describe it as "going underneath." It's not on the surface; you have to dig under.

In describing her in-session thought processes, one participant noted this type of attunement is client-centered and not linear. Rather, it more closely reflects the way clients tell their stories.

> I don't necessary follow an agenda, so I'm pretty willing to go with things the way the client wants to. I might be trying to keep track of a line of thinking that's related to the client's needs or agenda, but that doesn't mean I follow it. But I

> kind of, in my head, need to pull things together for myself. And I often try to do that overtly for the client towards the end. But that doesn't mean the session looks very linear. That's not how clients think of the story or want to interact.
>
> A great genetic counselor I think really works with the patient to hear what their needs are and then tailors the types of information and ways to provide that information based on the assessment**.** I guess, now as I'm talking, I wonder if it also is that assessment piece where you're really trying to use the patient to gauge how that session is going to go.

Category 2. Flexibility and "Meeting Clients Where They Are" (*n=12*)

For master genetic counselors, how a session unfolds is based on the patient. They regard this value of "meeting the patients where they are" as one distinctive aspect of the way they practice. Many participants commented on the importance of flexibility in tailoring sessions to meet clients' needs, even when those needs differ from what the master genetic counselor might have anticipated. Master genetic counselors are comfortable adjusting to patients' needs as they arise and are able to work flexibly within the complexity of emotional, psychological, social and informational realms. Participants' comments in this regard suggested pride in this flexibility.

> Genetic counselors know many things. And the quest, or one quest, is to figure out what you say to a patient out of all the things you know in your head, and how to say it. So it varies from session to session. That is a skill that may separate counselors one from the other in terms of how good they are, how expert they are.
>
> I think you can get from point A to point C—but I think that there's not just one path to do that. It's not to say you shouldn't have some kind of master plan here, but that it's not the same for every patient.

Several participants noted that honoring the collaborative patient relationship means that, by definition, sessions will be different.

> I think it's that every session should not look the same, because you're working *with* the patient versus *for* the patient**.**

> I certainly have that outline in my head, but I sort of use it as more of a suggestion, a guideline. If it seems as though one topic really is at the crux of what [the patient] is worried about, that's where we go.

> And some patients need more time, and some need stopping and listening and addressing an issue before a patient can hear everything you have to say.

Client attunement leads to flexibility in sessions and an individualized approach. The participants described an awareness of what clients are experiencing and then adjusting the pacing, focus and direction of the session, accordingly.

> I'm thinking about relating to the patient, or having the patient understand—internalize--so that they would take both the information and the context of the information and make it relevant to their own situation.

> I think I use creativity and flexibility in my sessions. And that's become increasingly important to me the more experience I have. If I go into a session with a checklist it has [just] words on it--a reminder to talk about reproductive or carrier testing. I have a list of words just to make sure I touch on things. But how I do a session depends on how it starts, and where the client is, how to create logic for that client, what their questions are. I want to know what their questions are. So, that kind of flexibility and what I consider creativity within a session is really important to me.

Client-centered flexibility can play out cross-culturally and systemically, as evident in a story one participant related. This participant noted learning the importance of being "flexible enough with what we want to accomplish--with what we *say* we want to accomplish--to be there for our families and our patients."

> We have to be even more flexible in dealing with our families who have tremendous burdens and have developed different coping styles. And we have to acknowledge that.

Meeting clients where they are can challenge master genetic counselors to balance the knowledge they have gained through experience, with ethical values, and patients'

desires. One participant described a situation in which a patient's request differed from the genetic counselor's professional knowledge. Although she was client-centered in her actions, the master genetic counselor used her professional expertise in the case of an adolescent who was "hell bent" on having genetic testing.

> She wanted to know did she carry this mutation that runs in her family. And my agenda is "Wow, a 15-year-old really shouldn't have this! Because it's probably not in her best interest." But I couldn't go in with that. That wasn't going to get us anywhere, to say, "You can't have this test." The only way to get anywhere was to come around behind her and walk forward with her.
>
> I went in with, "If you want to have this test, I'm going to help you get it. Most people wait until they're older, but if you want to do this, I will help you do it. But here are the things we have to do first; here are the hurdles that we together have to do to get there. The first thing is I have to tell you more about it. And then the second thing is I need you to meet with an [specializing] psychotherapist because we need to make sure this information's going to help you more than it would hurt you, and then the third thing is to go to the [clinic's] ethics board."

Category 3: Tailoring Salient Information for Individual Clients (*n=8*)

Genetic counselors work at the intersection of the *process* of genetic counseling and the *content* of genetic counseling. Those who excel in the profession do not necessarily provide all information to all patients. They selectively *tailor* salient and purposeful information for individual patients, and are attentive to and skilled at assessing patients' level of knowledge or readiness to hear and integrate information. They connect "science to the individual" and "avoid auto-pilot".

> There's no rule that says that you have to cover all this content. We think we do because it's been modeled for us, but I think that flies in the face of client-centered counseling, if we feel we have to include every item on the list.
>
> A good genetic counselor might cover a lot of the same topics, but I feel like with a great genetic counselor the difference would be *how* they cover that. I've worked with counselors who feel that every single piece of information is their job to disclose and discuss with patients in great detail. Versus I would argue that

> until that information is relevant to patients-- and relevant meaning they're ready to hear it, they want to hear it-- that's not going to be key to the session.
>
> Going back to that little biology lesson that a lot of us feel compelled to give in a prenatal counseling session [for example]: If a patient really doesn't have any scientific literacy, and is more concerned about if the needle is going to hurt or harm the baby, then we just talk about that, and we don't talk about meiosis and blah, blah, blah.

Several participants noted they are aware of and avoid going on "auto pilot" when presenting routine and standardized information.

> Even though I've counseled this same exact topic 400 times, for this family sitting in front of me, this is the first time they've heard it. And it's exceedingly important to them. So we need to somehow be able to manage the repetitive aspects of it by approaching each person or family as important.
>
> I try to be [self-reflective] even during the session. You know the thing about it is when you see a lot of patients, a lot of them are there for the same reason, so it's easy to go into automatic pilot. To some extent you have to because you have to share a certain amount of standardized information. But you've got to be careful there that you're just not always on autopilot.

Participants implied that they connect the science to the individual, rather than the science for the sake of science. One participant said she will "judiciously choose what not to include," and another talked about "not getting bogged down in minutia in a counseling session."

> One of my concerns is that there's a lot of "information dumping" that goes on now with genetic counselors. I have great concerns about that because I think it's very easy to come in a room and say, OK, I have to get from point A to point C and I've got to do it in 46 minutes.
>
> But you know, [an article] made me look at what we're doing in a different way. And to think, why do we have these mini biology lessons? I think they may serve us more than they do many of our patients. I think we're more effective if we can judiciously choose what not to include.

For a couple of participants judicious choosing sometimes means respecting clients' specific wishes by eliminating certain information altogether.

> I think [what stands out about my practice] is a comfort and a willingness to alter the format of a genetic counseling session to suit the patient. For example, there might be a patient who comes in and says, "Can we just skip the genetic counseling? I just want the test." And whereas in the beginning of one's career, a counselor might say, "Well, we really can't. We really need to do it this way; it must be this way, and you have to submit to this and that's it." Whereas, now I might say, "Well, we can consider skipping the genetic counseling. It would help me to know why, or what your main reasons for asking for this are." And then if I have a decent understanding [that the client is informed] then I'm comfortable to skip the genetic counseling.
>
> I also respect [clients] who say, "Look I know all about this, and I know what my decision is." I'm not going to spend 45 minutes going over it all again, just because that's my outline. I'm much more likely to say OK, and give them the five minute spiel to make sure that's really true, and then we just go with it. I feel little more comfortable tailoring things, or not following the rules.

A couple of participants noted that efficiently presenting information affects session length.

> One thing I came up with was efficient use with time, and by that I mean I don't overwhelm patients with words. Among counselors I work with it's commonly understood that my sessions are typically the shorter sessions, for better or worse.

Category 4. Sharing Information Gained Through Clinical Experience (*n=2*)

A couple of participants discussed their willingness to share the information they have gained through their clinical experience to help clients make decisions. These master genetic counselors consider such information a part of their expertise.

> What we've learned over the years, I think that to the detriment of genetic counseling in general, we started off with the non-directiveness which set us off a path that was unfortunate. But that grew into shared decision-making, and that really is a huge difference between a genetic counselor who's afraid to voice an opinion or talk about her experiences. And then one who says, "You know, I've

> seen over 400 families for predictive testing, and this is what I can tell you about that."
>
> I try to learn a lot of practical information to help my client. So in that sense, I love counseling for things that I counsel over and over as opposed to the counselor who's easily bored. [Where they might say] "Well, I've done 200 of these, why do the next one?" I feel like I have so much more to give my clients if I'm on my 200th case. Because then there are a lot of practical things that come from one client to another.

Domain 8. Inspirations

Despite the tragedy and loss they often experience with their patients, master genetic counselors find their work deeply fulfilling and tremendously intrinsically rewarding. Responses in this theme emerged from a question asking participants to talk about what inspires them as a genetic counselor. Their response in a word: Patients. Master genetic counselors are profoundly inspired by the families with whom they work.

Participants talked at length about their feelings of respect, awe, and humility inspired by their patients' resilience and personal strength. Despite empathically experiencing their patients' traumatic emotions, master genetic counselors are also affected by their clients in positive ways. Many participants implied a sort of duality of positive and negative emotions in working with clients. While feeling empathically sad they also experience intense respect. Participant master genetic counselors seem able to comfortably hold this these mixed or dissonant emotions.

Many talked about the positive impact patients have had on their own personal as well as their professional lives. Their responses indicate a two-way interaction within the counseling relationship in that master genetic counselors learn from their patients and integrate patients' experiences into their own perspectives on life.

Category 1. Inspiration: Patients (*n=12*)

Patients provide "a wealth of life experience and wisdom." Many participants talked about learning from their clients. For example, one individual learned "centeredness" from one family's resilience, perseverance and dedication.

> For years and years [a patient I feel close to] has taken care of a kid with [name] syndrome. As complicated as his story was, it was amazing that he lived [as long as he did]. But he lived that long because he had this mom--who was one of these people that I overstepped my boundaries with-- who did just an amazing job of taking care of him. Trach tube, the whole thing. And I would get up in the morning and say, I'm just feeling depressed today. But you know what? [The mom's name] has to get up today, and she's been up all night. And she's been suctioning that kid, and taking care of him, and she doesn't have the benefit that I have. If I really, really wanted to stay in bed an hour this morning, I could. But she can't do that. So all that stuff has kept me centered all these years.
>
> I'm humbled by what our clients go through and how they find personal strength and hope. I carry that around with me all the time. And I think it has affected my entire life and my perspective on all sorts of things.
>
> Patients give you a wealth of life experience and wisdom.

Another participant talked about her interactions with clients generating perspective on her own problems.

> I have this joke: I'd have a bad day, and I'd say, "God, why am I having such a bad day?" And that little voice would come to me—and I'm not a super religious person, I'm kind of a spiritual person—but God would say, "Oh, really? Let's go [to the clinic] and let me show you what a bad day is." And I would [respond], "I'm sorry! I was just kidding!" The ability to, you know, see things really could be so much worse. No matter how bad your day is, somebody's got it worse.

A lesson about assumptions was important for a third. As did several participants, she talked in a positive way about seeing this client grow from childhood into adulthood.

> One young woman who I've watched grow up had a baby with a problem when she was [an adolescent] and [faced several life difficulties as well]. And I watched her grow up and go back to school and then decide maybe she was going into [a medical profession]. I remember her talking to me [later] when she was [a young

> adult] and saying that when she [first] came to see me that I was the first person who talked to her with respect. I treated her as an individual rather than as a child who had made a huge mistake. And I remember thinking how impressed I was with her and how all of my assumptions and judgments about kids who had lots of surface signs of being very counter culture, how much she really helped me dispel those false assumptions. I was glad that she thought that I had treated her with respect.

Category 2. Inspiration: Patients' Resilience and Courage (*n=7*)

When asked about what inspires them, master genetic counselors express a deep respect for and awe of clients' resilience, courage, and "the dignity with which they meet difficult situations." Participants clearly respect the people they see.

> The resilience of families and the courage and dignity with which they meet difficult situations is an incredible inspiration. It's one of the great rewards we get from this profession.
>
> I think the patients inspire me. To watch people go through some really terrible things with such grace [is] very inspiring to me.
>
> And for all the reasons I've talked about with patients: their needs, their resilience, their hope is inspirational.
>
> [It's especially inspirational working with] people for whom genetics is probably not their number one priority. These are people who are trying to find a job and trying to avoid being gunned down in the streets and trying to not get pregnant and not be abused. And it felt relevant to help them try and figure out what was most important and what needed to be addressed right then and there. So I guess people inspire me, their issues inspire me, and I don't know how you could not want to do the work!

Participants also reported feeling inspired by the coping and empowerment they see in their patients.

> It sounds so trite, my families [inspire me], the people with whom I interact. When I see them getting a really complex concept or taking a step forward in their adaptation process.

> I'm amazed! Not so much in myself, but more so in just the human ability to grow and to change and to work with things. People are resilient and I am always amazed at being able to help, how patients are able to realize self-actualization for themselves.
>
> It's hard because you also see people who don't do well. But seeing people who've got these diagnoses like [disease] and they're in a wheelchair, they can't walk, they're unbalanced, and then they go out and do a triathlon. Like they say, "In spite of what this is, I'm going to go do what I want to do anyway." So it's inspiring to see what people sometimes do that challenges their "given."

Many participants expressed "privilege" and honor in knowing their patient families.

> I've been privileged to know these families.
>
> I have been really privileged to work in a [type of clinic] for [more than a decade]. I'm privileged to be able to know these families.

Participants also expressed awe of regarding patients' "grace" and "courage."

> Watching how families change [is inspiring]. I would say that it's common to think that you can't deal with something--until you have to deal with something. And that's where that courage, grace under fire, resilience and all that kind of stuff comes in.
>
> I love giving talks to patient groups and going to patient groups. I think that it's fun to go do that and have people really thank you for your contribution, and really be grateful. I think it's nice to have your effort appreciated. Especially--sometimes you feel guilty about it-- but quite often people are like, "Thank you so much for taking [the time to come]" You're like, Oh my gosh! You had to come here in your wheelchair, what I had to do is nothing compared to what you had to get here!
>
> They're struggling and dealing with these diseases and how it's affecting their lives and it's really amazing what some people can struggle through. It's very impressive to me. If I can help that in some way, if I can help them deal with that in some way, that's inspiring to me to [help]. What they're doing and the fact that I can help them**.**

Seeing patients "survive and thrive" is particularly rewarding, according to many participants. Many talked of experiencing tragedy with patients, but also experiencing the opposite extreme.

> It's like, how can you not feel good about working with families and see them come through at the other end of the tunnel? I think it just pushes me to keep doing it, you know? People say "How do you do this job? What a horrible job!" Oh really? Really it's wanting to be with--feeling comfortable in being with--families during such a difficult time, because you know that they will live through it. Just a love for working with people, and not being afraid of working with people when they're maybe not at their best.

> It never ceases to astound me the inner strength that humans have that we don't know we have. And I see these families not only getting through it, but thriving and leading reasonably normal lives and being able to make decisions to have more babies and raise other healthy normal children, and so people will pretty much amaze me.

> I think sometimes in the beginning you perceive that some of these tragedies or bad things are just sort of the end of everything. Because as a student, you see these snippets of really bad experience in people's lives. And it's not until a few years later that you see some of these people and realize that people put their lives back together and move on. So that's realizing that when you perceive everything's terrible, that's a moment in their lives, a snapshot or point in time, and it's not forever in their lives that way.

Being considered "expert" within some patient communities is also motivational.

> I think once you feel like you belong, in a sense, and you're a valued part of [a patient community] that, you get a lot of insights into the experiences and [it] gives you sort of a little spark to keep doing what you're doing. I mean, both from the standpoint of genetics, of being very actively involved in, gosh, these are people that I know! And I want to figure out something for them!

Category 3. Inspiration: Deep Personal Meaning from the Work (*n=12*)

Master genetic counselors find deep personal meaning in their work. Genetic counseling provides a "sense of purpose" and "meaning" and a feeling that they are making a positive impact in the world. In turn, this feeling provides motivation and fulfills a strong desire to help. In responding to a question about what inspires them, participants talked about an intense sense of gratitude at being able to help.

> I think that I'm inspired by opportunities to help, because it is gratifying and it gives me a sense of purpose. One of the things that makes humanity satisfied is if they can feel that something matters; it's a wonderful feeling.
>
> We're doing this to save lives and families. It's like there's something more important than us.
>
> At the end of the day, I think I feel like I've made a little positive dent in the world, so I think that really helps me keep it going.
>
> I think I realized that I had to do something that would make even a little bit of positive result in the world, directly.

Some talked about a personal connection in wanting to help, as well as a deep "satisfaction."

> Oh, it's a deep sense of satisfaction. Because we all go into this because really we want to help people. We want to make their lives a little bit better. If not their medical lives then at least their emotional lives and when you can see you've done that, that's great**.**
>
> Well, I continue to find after all these years, that the work is really satisfying on a regular basis. In a couple of ways: Because it's a helping profession and I enjoy helping people. And the emotional involvement.
>
> I'm just absolutely driven to do a good job for clients. I go in every time and I think here's a person to be known, and I know nothing about them, and how am I going to figure out enough about them to really [help].
>
> I am so energized on the days I see clients. I love looking at family histories, I love solving problems about what gene test to we need, or love working with families to give them the information so they can make good choices. Even when the sessions are emotional--once in a while I'll walk out and recognize that that was pretty intense.

Although they present it with humility, the participating master genetic counselors take great pride in "making a difference." For some participants this comes via patients' remembering key information that turns out to have a big impact. Others might value empowering their patients or making a difference on a deep emotional level.

> I'm always surprised when patients, 10, 16 even 20 years later, will say, "Oh, my god, you have no idea what a difference you made to me. "

> A couple of years later, I had [one family] come and talk to my students just as a family presentation. And it was fairly gratifying for me to hear them recount what they remembered. Almost every word that I had uttered, I think!
>
> They remembered some of the devastating things that they were told by some of the other members of the team. [And said] that I was like a calming presence for them, who was helping, not [like] a crutch, but helping them figure things out. And I think that it made me realize, reaffirmed for me, that what we say and how we say it really does have an impact. And that there's hope in most of the situations that we face. Even when things appear fairly devastating.
>
> It's nice to have people genuinely appreciate the effort you put in and to really thank you for being involved, and to recognize that you're really invested and not just doing this because you have to do it. So that inspires me, and it means a lot.

Having an impact in high-stakes situations is meaningful as well as rewarding to master genetic counselors. Several talked about interventions or recommendations that may have saved someone's life.

> A couple of weeks ago, this lady came in--she finally came in for counseling. She had her [test] and guess what? There was a [type of] cancer there already. But guess, what, it was teeny tiny. She is not going to die of [type of] cancer! Like whoo-hoo! If that was the only good thing that happened in my 30 years, OK, it was worth it. She is not going to die! We avoided it. It feels like being a teeny-teeny part of this really big thing. But that small part, it mattered.
>
> There're probably some clinical times when I've made recommendations to patients that wound up being helpful, like I think you should have this mammogram, or an MRI rather than a mammogram in your case right now. Then they find something that wouldn't have been found if I hadn't made the recommendation. And probably I get some ego-satisfaction from pulling out a clever diagnosis in people who've never had a diagnosis.

Category 4. Inspiration: Science, Learning and New Information (*n=8*)

The participants are inspired by the clients they work with, but they are also inspired by the scientific side of their profession. Participants discussed the rapid, dynamic and complex changes in genetic understanding and information, their passion

for being in the midst of it, and the learning that all of this inspires. Unsurprisingly, some participants reported inspiration from both clients and from science. Many participants reiterated their intellectual interest and curiosity as inspirational.

> I guess I'm probably different from some of the psychosocial people in that it's really the scientific curiosity part [that inspires me]**.** A lot of my job is work in [a lab], and so I think that really drives some of the passion.

> Generating new information, learning new information, science, figuring out something, some really complex concept--that inspires me. Learning. Learning really inspires me**.**

> The intellectual component of it is really my inspiration.

They are also inspired by the constant "dynamic changes of the job" and the explosive advancement in knowledge.

> One of the things that I've really liked about my job is that it's a moving target. And that the knowledge base is always changing. The things that you said to somebody about this condition three years ago maybe entirely wrong and our whole understanding of it is 180 degrees in the other direction. That sort of intellectual fascination, both with the information base and with people's responses to data and their situation has been remarkable.

> I think number one it's scientific, it's just fascinating! It's just a fascinating, amazing field where you're working…the gene is sort of the very blueprint of who we are, and realizing, it's such a fascinating time. You know people thought of the Human Genome Project, "Oh, we'll figure [it] out in a while." I mean the genome is just the story of who we are and how we historically moved around, and how we're related to all these other species on the planet, and it's just a fascinating science! To me it's like if you aren't interested, why would you do this?

> It's an amazing fascinating scientific field and it's just exploding in terms of the progress that's made in the last 20 years, and we're doing that in like two months now. So that really inspires me a lot.

> I think maybe another thing is just maybe loving the profession. I feel like I've been in this for [more than 30 years], and I'm never bored and it's partly because everything changes around me. Either I change because of what I'm learning or the knowledge changes certainly, really fast, so it's never boring from that sense. So that's kind of an inspiration being in a field that has such constant challenge and change.

A few participants suggested inspirations through more formal learning such as meetings, reading, and research. Teaching others was also a source of inspiration mentioned by a few participants.

> Well there are certainly things that I read that get me excited and inspired. Going to meetings, small think-tank meetings as well as larger national meetings can sort of really jump start the enthusiasm and excitement. Genetic counseling journal club, we certainly try to do that. I do quite a bit of clinical research and love research, and so for me a lot of it is just reading about something or hearing about something and getting that idea of "Oh well, maybe we could look at our population and see if they have this." Thinking about it with that mindset.
>
> I love to get people excited about genetics. That inspires me.

One participant described the interactive inspirations of her amazement with science and making science useful to patients, particularly younger patients.

> But the potential is there to use the science to do good in a practical way, to make someone's family's life, maybe a little bit better. In particularly because of with the hereditary risk, the [disease] tends to occur at younger ages, so these are people dying. It's developmentally inappropriate. When you're 70 or 80, lots of people die of [disease]. But when you're 30 or 40 or 50 you've got your young family, so taking kind of a complex science and applying it in a useful and practical way. Helping people not die if they don't need to.

Category 5. Inspiration: Colleagues (*n=4*)

A few master genetic counselors specifically mentioned colleagues as a source of inspiration. This inspiration comes from what they can learn from colleagues, both informationally and ethically, as well as from colleagues' resilience and efforts for the profession itself.

> I think seeing colleagues and picking up tips and things that they do really well is inspiring.

> Then when I see other genetic counselors who are out there pushing the limits--trying to think outside the box and see where genetic counseling can really go, and people who are sort of leading that charge. I think that inspires me.
>
> To watch other health professionals also handle things with grace is very inspiring to me. I have some genetic counselor friends who are very good and to listen to them talk about their own personal and professional issues, struggles and see how they've dealt with those kind of things is very inspiring to me.

Colleagues' personal characteristics are also inspirational. For example, one participant noted "selflessness" in a colleague.

> Seeing somebody say, "You know, I don't think I should be an author on that paper because I didn't do any work." Just refreshing honesty and integrity would be maybe another facet of the human side [that is inspirational].

Domain 9: The Emotional Impact

Empathically engaged with their patients, master genetic counselors are deeply affected the emotions they experience. They carry the "weight" of the emotional impact into their personal lives to some extent. But master genetic counselors develop means of coping (which are discussed in the following theme). Some participants also described positive emotional effects playing out in their personal lives, such as feeling nonjudgmental, appreciative and grateful.

This theme was primarily generated from questions asking how their work as a genetic counselor affects them personally, about the emotional intensity of their work, and how they manage the emotional intensity.

Category 1. The Emotional Impact: Loss, Sadness, Helplessness, and Communicating Bad News (*n=15*)

All of the participants acknowledged that their work impacts them emotionally. Most of the participants described feeling sad, distressed or "heart-broken"—or as one

participant described it: "The helplessness of life being unfair." According to these master genetic counselors, communicating bad news remains difficult and draining even at their advanced level of professional development.

> The emotional toll-- I think that there are some days that I leave here and I'm just really sad or distressed for my families.
>
> Now, do I ever take my work home with me? Of course you do. Sometimes you see things that are just heartbreaking.
>
> Certainly on a particularly bad day or now that I've been working in [disease], when you just think, "It's not fair" even though you know the world is not about being fair. When you see some really just terribly, terribly tragic things, when bad things really happen to good people.

"Draining" was the word many participants put to the emotional impact of their work. Tough cases involving children, are particularly so.

> I think it's draining. You're often involved with people at one of the very low points of their lives. I mean whether it's a child whose got [disease], or realizing that it's a disease that their kids could get, or with neurology, losing their independence. It's harder to be super duper engaged with that but not carry the weight of it.
>
> I mean, it's definitely draining. Especially the days when you have tough cases, and they're babies with sad problems, or kids with sad problems.

Repeated experiences with traumatic cases can impact perceptions of what is "normal."

> I couldn't believe that people really had normal kids, because I really never saw that. So I had such trepidation having kids.

Several participants talked about the loss they experienced when working with patients they had felt close to, knew well, and cared about.

> I got very, very close to a few families, and when their [family member] died, that was hard. I think it is a loss for me. And partly because [engaging with families] is one of the things that I love about the field.

Some participants find themselves feeling more emotionally connected and invested in patients for whom the risks are higher. Those are the ones they may be more likely to think about outside of work.

> The ones that I tend to be more involved with are the once who are at high risk. So luckily those are smaller in number. It's not like every day we're dealing with these high risk patients. So they're smaller in number, but your investment is higher, and the opportunity to help them is higher. These are the people I'm more likely to think about outside of my work hours. I don't think about them all the time when I'm at home, but I do think about them outside of the [office].

> They come to us with 25 percent risk of having a child with a genetic condition. Or, even 50% risk. And the patients who have fetal anomalies. They had a sonogram and there are abnormalities. Trying to figure out whether to have amnio or what tests to have, those patients I get emotionally connected with.

In describing their feelings of loss, most participants told their patients' stories. One participant told of working with adolescents whose parent had died of a particular disease and whose brother was also terminally ill.

> So their dad had asked us to see them because he was concerned about any potential relationship between his wife's early [disease] and their brother's [disease]. I was seeing [one sibling] and her [sibling] was being seen by my colleague at the same time, because their brother, who was turning [age] that day, it was his birthday, had a rare [type of disease]. Really rare. And was not going to live. And their mother had died just a few years earlier. And that's all I knew about them. So I was meeting with the family and asking questions about her mom, and what had happened with her mom. It was a really moving story.

> So in those days, that was back when pregnancy terminations really involved a labor and delivery. And sitting down with those parents and thinking, there's nothing normal about this fetus, but we've got to find something. And talking to the families and encouraging them to see the baby, which literally I almost got fired for. Because, I mean, this is really a fetus that was just really horribly [deformed]... it had, it was just... yeah. And later, going back the next morning and the dad saying, taking a pen and drawing on a paper the foot of the baby, which was probably the only normal thing on that entire fetus and saying "The foot was so beautiful."

A few participants noted experiencing an emotional impact as supervisors hearing patients' stories from supervisees. A couple participants also noted helping other medical colleagues cope with the difficult emotions involving genetic patients.

> Some days things are hard. Now I listen to more cases of my students work than I see patients, I still see patients, but not as often as they do. And I wake up in the middle of the night thinking about their clients that I never even saw, but I've listened to them on tape, of how their life's been affected in some profound way. And it certainly makes me sad.

> I think part of [a particularly difficult patient experience] was overcoming my own fear in helping other professionals in overcoming their fear of what was happening to this patient.

> You know I watch the physicians who take care of the kids with the in-born errors where things get worse and worse and worse, and it wears them down. It just wears them down. Sometimes it seems they are avoiding being direct with the family because it's just too wearing. I've not really experienced that.

Even at a high level of professional development, communicating bad news is difficult, draining and distressing. Master genetic counselors expressed feeling distressed when they cannot provide the positive news they think people deserve. One participant told a story of figuring out a diagnosis for "a nice family, great parents" with whom she felt very connected. The couple was newly pregnant, and she would have to tell them a diagnosis that would eliminate the hope they held for a less devastating diagnosis for their older child. The participant knew she would be revealing information that meant "their life would never be the same."

> I think part of me was really distressed, because they were a really lovely family, and phenomenal parents, and just really charming. I think that I was able to deal with the part of me that was really distressed by this child's diagnosis, but really terrified at having to break this diagnosis. And the mother was pregnant… I felt completely drained when it was done.

> So I think one thing that's hard about the profession or how it affects me: It's hard to be really passionate and engaged on something but then also have the off switch. To say, you also have to be able to turn it off and walk away and go do something else. If you're passionate about it 24 hours a day you're just going to go nuts.

Category 2: Positive Impact on Personal Life (*n=3*)

Some master genetic counselors talked about their work with clients having a positive impact on their own lives. A few participants said they feel they are much less judgmental in their personal lives, or that their understanding of others translates to their personal life as well. For example, one participant told a story of having understanding for a friend who was considering placing [a family member] in a residential facility.

> I remember one of our other friends said she can't imagine [doing that]. "What a terrible thing to do and how could she do that?" I think I went a little further down the path and was able to figure out the torment [the first friend] was experiencing, and her drive to do something better for her [family member]. So I think it's made me become less judgmental in my personal life. I think that really has translated. I've heard a couple people say that they think that I'm very nonjudgmental and they think I'm very supportive.

Others find they are better prepared to handle grief in their personal world. One participant expressed dismay that a family member avoided contacting a friend who had experienced a loss.

> I'll just give you an example in real life that happened [recently]. A very close friend of a friend of ours died very traumatic, relatively young. So the friend calls to tell me, and I ask my [family member] to please make contact with our friend today. And [the family member] said, "Well, I don't know what to say, I don't know how to do that." I thought, "You don't know how to? How pathetic!" I wasn't asking a lot, even an email would suffice. It was just communicating, reaching out. And how often we have trouble doing that.

Several participants reported that their work dealing with fetal anomalies makes them feel very grateful for the health of their own children. They feel "lucky."

> Then this "centering" that I've had from our families, who are going to have kids with problems forever, family member with problems forever. And how grateful I am to have the family I have and their normalcy, the normal problems that we have, without those that are just intractable.

Another talked about her reactions as a genetic counselor in a newborn nursery and "dealing with all these babies with birth defects."

> I'd like to emphasize, I feel working in a field like this--I must have this thought every day – that I'm so lucky. That I think it really gives us such a unique perspective of being blessed by healthy kids. My [spouse] is [in a related field] so we kind of share this sense that we were really damn lucky. You know the ax can fall at any moment, but so far, we've been lucky and we really recognize that.

> I think about [parents facing difficult concerns in their children] a lot and think about how fortunate I am that my kids are healthy. And that my marriage is healthy and all of that. That my whole life is basically easy.

Category 3. Managing the Emotional Impact: Emotional Boundaries and Compartmentalizing (*n=10*)

Participant master genetic counselors' acknowledged that the intense and "heartbreaking" work sometimes affects their personal lives. Participants seem able to "absorb" the emotional experience of their work while also managing it without undue stress.

The coping methods that master genetic counselors described using, and which likely play a consummate role in minimizing the effect of their work on their personal lives, include: balancing emotional investment with appropriate boundaries, and separating one's professional and personal lives. This theme was generated primarily from questions asking how their work as a genetic counselor affects them personally, about the emotional intensity of their work, and how they manage the emotional intensity.

Most participants noted that they cope with the emotional impact of their work by balancing their emotional investment with appropriate emotional boundaries. Boundaries help them cope with the emotional intensity of the work.

A couple of participants identified successful emotional boundaries as a defining characteristic of master genetic counselors.

> [A master genetic counselor] is probably someone who's able to balance being emotionally invested in their patients but not taking it home and weeping and sobbing every night. So they're able to appropriately be empathetic and invested emotionally in patients, but also maintain appropriate boundaries so that it's not something that takes over your life.

> We're all empathic and that's why we go into this, and you've got to soak in some of that emotion. I think ultimately, most of the time, you learn to keep the devil down in a hole there. You don't let it overly obsess your life. That's not good for you. And some will bug you or make you feel better more so than others, but you can't let it rule your life.

> With the emotional issues, I guess I've learned to keep them in perspective. I mean, there's always a day when I'll go home at the end of the day and it's like, oh god, you're just drained emotionally from it. But I wake up the next day, and on to my job again.

Many noted they are able to maintain emotional boundaries by "compartmentalizing" or implementing an "off-switch." This strategy of coping and self-care provides a way to leave work at work. Some attributed their ability to maintain emotional boundaries as a part of themselves; others attributed it to their overall good emotional health.

> I think for the most part the sadness that you deal with, you know, patients' losses; I'm able to deal with that somehow. I guess I can kind of separate their situation from my own.

> You know, as tough as this job is, I want to say it affects me. But there is some—but maybe again it's just who I am—but some ability of me to compartmentalize a little bit.

> I can go home and say it's awful what these folks are dealing with, but it doesn't emotionally tear at me. I think I've learned, or forced myself to compartmentalize, and work is work, and home is home.
>
> Over all my emotional health is good. When things are going on, I think I do a good job of separating those issues from when I'm at work, or at least from when I'm in a patient session…

Others described a philosophical view that helps them cope.

> My students have a really hard time with giving bad news, and I think some experience with that and just having the attitude, this is bad news, but you didn't make up this news. Yes, it's difficult. Yes the client might blame you for it. But if you're skillful, you're going to be the right person to give them that news.

Category 4. Managing the Emotional Impact: Separating Personal and Professional Lives: Work Is Work and Home Is Home (*n*=6)

Participating master genetic counselors also discussed maintaining a work/life balance. They are aware of boundaries separating their work life from their home life, their professional life from their personal life. Many participants talked about "leaving my job at the office," or "when I am at work, I'm at work and when I'm at home, I'm at home."

> We've always had the rule in my house and it drives my [spouse] crazy, so it's maybe not been helpful to my marriage, but I don't like to talk about my job at home. I like to leave my job in my office. I'm not always very successful at that; I am the kind of person that wakes up in cold sweat in the middle of the night. And certainly it does affect me sometimes. But I've always had to go home and be a [parent]. And in order to do that I had to leave some of this in the office. Which I think professionally is healthy. So I do have an ability to kind of compartmentalize. When I'm at work, I have to be at work, I can't be worrying about my kids. I have to kind of carve out these different time periods.
>
> The emotional toll-- I think that there are some days that I leave here, and I'm just really sad or distressed for my families. But most of the time I have been able to leave at least the bulk of that here. And that when I go home-- when my kids were younger when I was home maybe I was more tired or not as patient with them, but I didn't feel like I was thinking about work a lot at home.

Some participants talked about "protecting family time" while also acknowledging the stress of "always being behind" and giving themselves permission to *not* work at home. These responses also may represent a balancing of values around "doing good" in the world and a happy family life.

> I try not to work on the weekends at all. Which is helped by the fact that my [spouse] works on the weekend so I have the kids. [Laughs] I used to take a bunch of stuff home, and work on stuff all weekend. And you sort of realize eventually you're going to be behind no matter what you do. You're not going to get it done, all you're doing is just taking away your away time. So I try to really protect that as distinct. I think the most important thing is to be OK just saying there's time when I'm not doing any of that work.

Sometimes not taking work home relates to the difficulty that non-genetic or non-medical family members might have in relating to it. One participant said it is hard to talk to family members about her work life because of the effort it requires to contextualize it.

> I think it's too complicated, you know? To explain things to someone who's from a different work environment? It just takes too much energy! And at that point I just don't have the energy and I don't want to explain it or try to contextualize it so that I can get [family member's] support. I think I just… if I feel sad I want to feel sad, or I just leave it because there's not much else I can do about it. But I tend not to talk a lot about it because it's just too hard, to convey the nuances.

Other participants noted that the work concerns that are more likely to bother them at home are those they have control over such as their own performance or if they realize they have given inaccurate information.

> The only time it kind of haunts me or I worry about it is if I will get home and realize I may have done something I shouldn't have done, either by giving out inaccurate information or said something in a way or phrased something in a fashion that could in some way be interpreted as being disrespectful of them or whatever.
>
> Like a mistake, or maybe just not getting back to them when you should have, or something like that. I think it's harder to manage actually, because then you're

> responsible. And there you just have to forgive yourself, saying, there are going to be times that those things happen.

Category 5. Additional Coping/Self-Care Strategies (*n=8*)

Some participants mentioned additional, specific self-care strategies they use to cope with the emotions provoked by their work. Some said they chose a less intense work setting or one that provides variety as a way to lessen the emotional impact. More participants described self-reflection, physical activity, or journaling. Many of these participants mentioned more than one means of coping and several said they use their strategies in preventative ways.

Some use physical activity for self-care.

> I exercise or run or work in the garden.

> I actually [work out] in the morning to clear my head so it's clear for the day.

Several participants mentioned self-reflection or just letting themselves feel what it is they feel.

> [After a day of working with tough cases], as talkative of a person as I am, I tend to go home, and [in the evening] I just need some quiet time. I've talked all day and I don't want to talk.

> I do a lot of journaling. It kind of lets me say the things I wanted to say, or think about the things I didn't say.

> I guess that sometimes I just go with whatever I'm feeling. If something is following me home, if I'm feeling sad, I just need the space to kind of dwell on it a little bit. I may not try to dispel it.

Others noted the resilience in their own personality, gaining strength from their own family, or fit with their work setting as ways they cope.

> I don't know what process I go through so much as I guess I have a strong base to my personality, and I have a family that I love, and so that's where a lot of my strength comes from.

> I think that the setting I work in,--I mean it'd be so much different if I were in like a [specific disease] clinic. I think that would be a lot different.
>
> I love to teach. I mean if I couldn't teach that would probably make my job a lot more difficult.

To help them maintain emotional balance, some participants described philosophical perspectives such as understanding their own limitations and even forgiving themselves of those limitations.

> I think first of all, the ability to let yourself be humbled helps with the job not killing you. I think the ability to understand that it's not really about you allows you to compartmentalize a little bit.
>
> So this is something…I thought a lot about early in my career. I pretty quickly came to the conclusion that I didn't create my clients problems. So as long as I didn't create their problems, I feel I can separate that and take the attitude that either my skills help them or my skills don't help them. Their problem exists outside of me, in the world, and I either leave them there struggling with it alone, or have enough skills to help them with it.

Still others use a realistic appraisal of predicaments that are simply a part of the profession.

> Sometimes when you think you're doing a really good thing, it doesn't necessarily mean a good outcome.

Category 6. Monitoring For Compassion Fatigue (*n=7*)

Many participants mentioned symptoms of compassion fatigue and self-awareness in monitoring their levels of emotional health. Interview questions did not specifically ask about compassion fatigue, but in discussing the emotional impact of their work, about half of the participants spontaneously raised the issue of compassion fatigue or of potential for burnout. A few acknowledged having experienced mild burnout at some

point in their career. None spontaneously acknowledged having experienced compassion fatigue.

> I can't say that I've ever felt burned out with the level of emotional needs of patients. I feel stressed because of trying to meet those needs, but never felt less compassionate about it.

> I don't think I've ever experienced true compassion fatigue. I've had kind of like mild burnout where I was just fed up with everything, but it was more about [work site] issues than counseling work.

Some participants demonstrated an awareness of symptoms of compassion fatigue and self-awareness of the importance of monitoring their levels of emotional stress.

> When you don't have the energy to talk to another client. That happens to some of us to some extent, but when it's happening nonstop that's the time you have a problem…. When it's spilling over into your private life and your interactions with your friends and your family and colleagues, that's when you know you have a problem.

> I'm not depleted by my work. And if that changes then I would need to make a change.

> I've always been pretty good at being emotionally healthy around the stress of what I do, and that includes working in some really stressful situations.

Domain 10. What Constitutes "Success" in Genetic Counseling?

The following categories arose from two related questions. The first question invited participating master genetic counselors to take a moment to recall one of their most successful cases and reflect on what about it made it successful. Then they were invited to talk about how they know when they are doing a good job with client*s*. According to participants success is predicated on being patient-centered, providing information, fostering clients' empowerment and competence, providing guidance, and

facilitating insight and meaning. Ultimate “success” for master genetic counselors comes when patients make decisions with which patients are comfortable.

Category 1. Success is From the Patient’s Point of View (*n=10*)

Master genetic counselors define success in a patient-centered way. A majority of the participants specifically noted that what constitutes “success” must come from the client’s perspective.

> I guess success, I have to define success first. My definition of success might not necessarily be the same definition that the families are using.
>
> I don’t think [success] is about me. When people can’t remember my name but they got something out of [the counseling], that’s OK.
>
> I’m often intrigued by how families will be overly thrilled with the services they got with the interaction, when it seems to me, I didn’t really do anything so terribly remarkable or that I would have perceived as helpful other than to listen.

Some noted the impact on the patient’s life is important in determining success, as did one participant who talked about a client who was “finally able to do what she needed to do to take care of herself.” Another participant reflected this point in her statement that she felt successful:

> When, at the end of the session, I feel that somebody has made a decision that's right for them.

Category 2. Successful Genetic Counseling is Multi-Faceted (*n=11*)

As with the counseling relationship, master genetic counselors view successful genetic counseling as multifaceted. In reflecting on cases that they thought went well, participants identified several interconnecting components of successful genetic

counseling. The components included providing information, but also connecting with families, facilitating decisions that feel right to clients, finding solutions, and providing emotional support.

> So, in general, clarification of information, lessening their confusion, insight into their decision are all things I would think of as aspects of what I might call a successful case.
>
> So I feel like I was able to get across the information that I needed. I was able to help them made a decision they were happy with. In terms of testing I feel like they were able to come to the decision that was right for them so that's a big part of [a successful case]. I felt like we did have a connection and so that they did feel comfortable asking me quote, unquote stupid questions.
>
> I think it's helpful to be solution-oriented. And I think with clients it may play out as you can support them and give them information but helping them find solutions is another kind of activity.
>
> If [clients understand what we've talked about], are able to use that information to make decisions and feel reasonably good about it [genetic counseling is successful].

Category 3. Components of Success: Information leads to informed decisions (*n=6*)

For master genetic counselors, providing information plays a key role in successful genetic counseling. Several participants said that "success" means that clients "feel well-educated" and understand information. Some master genetic counselors expressed that, in turn, understanding leads clients to feel capable of making an informed choice for themselves. Thus, these participants indicated they see an important role in clarifying information or reducing confusion, and they connected understanding information to patient efficacy.

> When people leave I think they feel well educated. I think they feel, "Oh, I do understand this!" Almost like self-efficacy, "I can get this. I get this. Even

> though I'm not a scientist, I can do this! I get it." I think they feel well-informed, and I think they feel capable of making an informed choice.
>
> And when she was informed [about testing], she was like, "You know, I don't think I need this right now." I'm like, hooray! Because she was able to come to it. She was able to conclude that herself. And she felt supported and informed. We were on her side. We were helping her get what she needed.

Category 4. Components of success: Fostering empowerment, efficacy, and competence (*n*=4)

Others participants more explicitly discussed the importance of empowering clients, supporting their competence, and fostering efficacy. For example, one master genetic counselor talked about working with clients who might be afraid of losing their independence. In cases such as this, the participant said, successful genetic counseling involves guiding clients in coming up with their own solutions rather than the counselor dispensing them. Guiding clients to discover solutions for themselves requires creativity and nuance in structuring the process of the session.

> You know some counselors think they're really great if they can give all these great ideas to clients. But it may be more helpful for the client to come up with the ideas. That you structure the session for them to be creative rather than for you to be creative.
>
> I use a lot of anticipatory guidance. Meaning you know something's likely to be an issue so you bring it up before the client does. I'm interested in supporting client competence**,** so if there's a way for the client to come up with an idea as opposed to the counselor then that's fostering client competence.

Fostering empowerment sometimes requires challenging clients.

> Say I have a client who, because I'm doing some psychosocial work with them, I discover that they're really worried. I see a lot of [particular disease] patients so I have a lot of clients who are worried about losing their independence. So you can listen…but a more solution-oriented approach would be to say something like, "How do you get around? Do you drive everywhere? Do you ever take public transportation? Do you know about the bus system in your town? Do you think you could in the next month, take your family out to a movie and everybody ride

> the bus?" So I'm thinking, here's somebody who's afraid of losing their independence, a lot of it has to do with driving. It's a huge thing. So why not introduce things into your life that kind of expand on that and might last a little longer than the ability to drive. It's really making it practical by challenging the person to actually take a step.

Another participant talked about successful genetic counseling resulting in a more psychological sense of efficacy.

> I had a patient the other day in [type of] clinic. And in talking with them about what this new diagnosis means, I could just see a little bit—not a lot—of [the parents realizing] "I can do this. That [my] child is not going to have such foreign medical needs that I'm not going to be able to cope with this, to be the best parent that I can for [my] child." So I think if I can work with families and foster that [it constitutes success].

Category 5. Components of Success: Patients Gain Insight, Perspective, Understanding, or Find Meaning (*n*=5)

Several participants discussed their successful case as one in which patients gained insight, perspective, or understanding.

> Like when [patients] say, "Gee, I didn't realize that, that's a different angle on things." That's when I feel like, "Ah, I've really done something here." I don't have to change them as a person, I don't need to change everything about their medical care, but if I can give them some insight that they previously didn't have, or some perspective they previously didn't have, or even a little gem of knowledge or information they didn't fully understand or appreciate how it affected them, that's when I think I'm helping them.
>
> So I guess when I help somebody to a self-realization, and it doesn't have to be life-changing, it can be small.

Other times the topic is larger and more existential. As one participant noted in cases she sees as successful that "families will engage in kind of big picture, deeper discussions about what [an issue] means." Another participant described what she considered a successful session involving a client gaining powerful, cross-generational

insight around a hereditary disease. This genetic counselor found the client's emotional processing within this successful session to be very inspiring.

> We had a woman who found out she carries [a particular] gene, and she was just agonizing about her [children]. She was agonizing knowing that this could be passed to her children and that could happen through her. We know logically we don't choose the genes we inherit; she didn't get to choose that. And what was interesting as we talked about that, and brought it back to [the fact that] this gene came from her mother. I asked, "How do you think your mother feels? Do you think your mother feels this way, too, when she looks at you? What could your [children] say to you that would make you feel better? Not that we're going to ask them to, but what would it take to make you feel better?" And we ended up deciding, she decided, to say out loud to her mother, that even if it means having [this] gene in my family, "I would still choose to be your daughter." Anyway, some of that stuff is really, really amazing when it happens, and we together come up with elegant and meaningful solutions for a family

Category 6. Components of Success: Providing Support and Facilitating Coping (*n*=5)

Some participants talked about successful cases in which they provided support for patients. For example, master genetic counselors feel successful when they are able to deliver bad news in an effective way and help clients adjust.

> I think if I'm able to see growth in a patient. And what is a sign of growth? I have no idea. Sometimes I think it's very subtle. If I have been able to walk with a patient through a pregnancy termination or a continuation of a pregnancy with different health concerns, and seen them go from complete crisis to coping with their decision or their new child.
>
> So being there next to them to help them, support their choices and help people get what they want. And by doing that, we move forward together.

One participant described giving negative results in small doses as the patients could emotionally and psychologically absorb it.

> I felt like I was there for [the family] and was able to help them cope with the new situation that we were facing. To be realistic about it, but without dumping what

> the whole future was going to be, that they could only process a little bit of the information at the time. So trying to do that and re-contextualize what their lives were going to be. How things were going to unfold for them a little bit and to let them know that I wasn't going to desert them, even though they were now going to be looked after by a different team of health care providers.

Category 7. Components of Success: Trust and Relationship (*n=10*)

Responses in this theme generally arose from a question asking participants to reflect on one of their own cases that they considered particularly successful, and talk about what they thought made it so.

Overall, in discussing cases they viewed as successful, master genetic counselors emphasized "making connections," building trust, and creating relationships with patients. Participants described many different ways in which this plays out. For example, one participant described a successful case as one in which patients feel comfortable calling back or "to ask 'stupid' questions." Others discussed being in "an honored position" as a patient's confidant around genetic issues or creating the safety and empathy for patients to express emotional pain. Several discussed successful cases in which they provided an on-going relationship with patients or families, describing their own role as that of "consultant" or a "trusted guide."

One participant described a session she considered successful based on having created a safe space for a couple to talk about their concerns.

> I think when I worked with a couple that I am doing a good job when I see the couple turn to each other and start a discussion. And I've had students say to me, "Well, they just started talking to each other, this is a really negative thing." And it's like, if they're talking to each other in the session, that means they haven't had this discussion before a lot of times, and so you've created this safe space for them to have a discussion. Now, that's not a general thing, that's a very specific example [of successful counseling].

Participants concurred with the importance of trust in success in genetic counseling. Trust is necessary for patients to feel secure in calling back for additional information, and also so that they can trust the information genetic counselors provide itself.

> Not every session needs to be a super-deep exploration of emotions or whatever or psychosocial issues. But [it is successful when] they have a sense of trust in me and that they'll call me to ask me questions so that they're either not afraid of me or they have enough trust that I will not misguide them but try to address their issues.
>
> Well, I think that what I'm trying to achieve is for people to be able to call us back. That's what I think is successful. We are trying to build connections. In the old days I think we really didn't do much more of a one-shot thing. We either made a diagnosis or not. But now with evolving genetics and testing the way it is and repeated testing and the increase in technology, we want to make a connection.

Other participants reflected on successful sessions being ones in which patients felt safe to reach an emotional place they hadn't been able to process previously.

> I'll probably get emotional. Oh well. And I don't even know how to express it very well. But there are moments… there are moments of light. I've got to grab a Kleenex, hold on… [long pause] but some of the things that are so amazing is the privilege I can barely even tell people about this one. But there's a woman who needed to relive the day her toddler died...of (disease). So it was a family with [genetic issues]. I don't know how we got there, but she told me the story of that day and she said she had never told anyone. What a privilege to allow that to come through. Things like this are special moments. I don't know how to express this, once in a while something just goes really right, and those are just these moments of light.
>
> Another thing would be if a client reveals their personal feelings, if they're comfortable talking with you.

Several master genetic counselors mentioned the positive reinforcement they gain from on-going relationships with patients, or when patients remember information from earlier sessions and are able to act on new symptoms.

> Like today my patient called me--this made me feel amazingly wonderful--this kid is [an adolescent] and has [disease]. Mom just checks in with me periodically. But lately the kid's been having [specific symptoms]. So they go to the pediatrician, and [the mom] said in the back of her mind she heard my voice: That if [name] starts developing symptoms and she needs a [particular medical procedure].
>
> That the mom remembered me saying that made me feel great. Because it was a connection that she had with us that she was able to call, to remember what we said, and now they found something. And of course she's scared and doesn't know exactly what it means and everything, but she's made the connection enough to know to call me back.

Some participants view their most successful cases as those in which they build a strong relationship with a family and became an on-going resource. Some participants talked about successful cases in which their relationship with the patient extended over years, decades or generations

> The one that came to mind is a patient I had about 20 years ago who stays in touch. It's a woman who is very well educated who had an amniocentesis; her baby had [type of] abnormality. The couple continued the pregnancy and have remained in touch for 20 years by email, going back and forth about [information] she had found, what my reactions are to things in the literature.

This participant, too, felt she was in an honor position in being able to be a confidante for the family in this successful case.

> [The family] had a big on-going question about whether to tell her child about this finding, so it's a very unique thing. Very few people know of this finding in her child, and I'm one of them. And her pediatrician is one of them**..** Even though she's completely gone from the area, she's still stayed in touch.
>
> ...And then to have that longevity. Very unusual in a prenatal setting. Most interactions are one pregnancy, one session. Other patients several pregnancies, but in this one particular situation to be in touch for 20 years. It's not like I remember that one counseling session very well, it's just the longevity. And that I'm in a very unique position. I think it's that she has trusted me with this relationship for all these years. That she feel comfortable including me.

In describing a successful case, another participant talked at length about her role as a "trusted guide" over the years**.**

> I think one of the reasons this case was satisfying is because I worked with the family over years. So I had the opportunity to really build a trusting relationship in multiple encounters.
>
> I feel like I was kind of a guide for the family. One that they could go back to, and they have over the years. They really saw me as a resource in this difficult [situation]… So they had a strong sense of the knowledge, not necessarily me, but the knowledge as saving their lives. So, I guess it's being involved in such a kind of high-stakes situation. Being able to have a great relationship with the family, and be a resource for them.

Others discussed issues such as successfully negotiating with families about who to test or the timing of testing younger family members and doing so in a respectful manner.

> I was trying to think what made it successful. It was a case where somebody contacted me and wanted testing, I had to negotiate first of all with him about testing his [relative] who was the right person to test, and that was successful. And she came in and had testing, and we found she had a positive mutation, and then I worked with the family. I think I was really flexible with this family [that] is sort of the reason it was so successful. And they trusted me to do that.

Category 8. Interactive Engagement (*n=12*)

Responses in this theme were generated by the question "How do you know when you are doing a good job with a client?"

Almost all of the master counselors identified ways they have developed to gauge the effectiveness of their counseling, and they do so primarily via the counseling "process." They know they are doing a good job with patients when they feel a sense of connection or emotional attunement, the counselor-patient dialogue is interactive, and they see patients gaining understanding. They accomplish this by encouraging patient feedback, and monitoring patients' verbal and non verbal communications.

Others described knowing they were doing a good job through patient's reactions, such as when patients are engaged and asking questions, volunteering information and

pulling pieces of the conversation together. A couple of participants referred to this as "seeing light bulbs go off."

Many participants described knowing that they are doing a good job—or not--with patients based on a sense of connection, understanding or emotional attunement. It can be a "subtle" and "intangible sense."

> [Knowing when I am doing a good job with a patient] is very subtle. It's a sense of connection, a sense that I understand them. Or when they can reflect back to me that I've understood them. Or I've pressed a button and they cry. It's the sense of knowing what it is that's really bothering them. Or being able to see the world as they see it, whether that be humorous, or whether it be from a very sad diagnosis standpoint. It's just a sort of a subtle intangible sense that, "Yeah, I get you."
>
> I think you do it for a long time, you read the feedback after you've sat with people for X amount of time, you sort of would come out of it feeling like, "Gosh, that wasn't very satisfying." And then you just sort of try things another way, and ah, that sort of works.

Some participants described intuitively picking up on awareness of nonverbal messages from patients during the session, which allows for adjustments as needed.

> I mean sometimes you know the vibe is there. It's just the gestalt of the patient's eyes, their face, the tenor of their voice, what they're saying, you put it all together and you kind of pick up on, "Oh, I'm not doing something right here, I don't know what it is, but it isn't right," or just the opposite, "Well, I guess I got though to this one ."

Category 9. Interactive Communication (*n=9*)

Other participants said an interactive dialogue indicates they are reaching the patient. Many noted that it is much easier to assess a patient understanding or whether their presentation is effective when there's interaction.

> Well, when there's a two-way dialogue. You know sometimes in a session you get nothing back. You're talking, talking, talking and you're getting nothing back. It's less easy to see how you're doing, harder to assess what's being

> understood, whether your presentation is effective, where they are. I think you can sense better if you're doing a good job, or a bad job, with a client when they're saying something back to you, and it's a two-way dialogue.

> [In a particularly successful session] there were parts of the conversation that were very conversational style, so it wasn't as though I were lecturing and they were passively listening. It was much more didactic and that feels good, too.

Others described a reciprocal engagement as the means they use in determining how successfully the session is going. One participant described her own use of self—a felt sense of engagement--when both the genetic counselor and the patient are showing genuine interest, the communication is going well.

> I think it just feels like, you feel very engaged, like you are really interested in them and their story, and not just checking off "I've got to ask you this, and this, and this." They're asking questions and they're showing that they're really genuinely engaged in the process. Maybe you feel like you've communicated a particular point well. Part of what you do is you have to explain some technical things and you see that light turn on. When you have the moment you sort of realize, you can communicate this effectively. And you feel like they really "get it".

> I can usually feel when someone is engaged. There's kind of a rhythm of the interaction. And when that rhythm is going smoothly, they'll be asking appropriate questions; they'll be interjecting their own analogies like, "You mean like, this…?" You get feedback--sometimes direct and sometimes not.

> It's the times when people are clearly hanging on your words, people are asking lots of intuitive questions and are raising issue. You've sort of started the process of "How do you want to deal with this? How do you feel about this? What are you thinking about this?" And they're volunteering stuff over and over and over again, along those lines. So I think then you really know it's working.

Interactive sessions are important in establishing mutual and collaborative goals, noted one participant. This participant said the genetic counselor and patients "come to the same place of what we want to get out of the session."

> When patients are very engaged in this, they're in the driver's seat. It's being comfortable to let them go with their agenda, not my agenda. I think [genetic

> counseling is successful] when they feel like "I got to decide what we were going to do and talk about."

Category 10. Patients Integrating Knowledge (*n=5*)

Others participants talked about seeing patients integrating knowledge and asking meaningful questions. One person described seeing "the evolution in their thinking" and mastery of knowledge as a sign of successful counseling.

> When I see them pulling this all together and giving me verbal feedback that, "Wow, I never knew that [there were other options], or "Wow I never knew this genetic testing was out there."
>
> Good client questions. When you have clients that ask really good questions and it's obvious that they haven't thought about it before. You're kind of seeing evolution at work here, in the sense of their growing knowledge and mastery so that they can ask these good questions, that can be a sign.

Participants said it's meaningful when patients reach an "ah-ha" moment of gaining insight.

> Really, I think that moment in session when you see the light come on in a patient's eyes. Where you can see they realize, "Oh, wow, that's right! I never thought of that. Or, "Oh! That's what I need to do!" or "Nobody ever told me that" or "What I've been thinking up to now is wrong, or inappropriate, or not what I need to do for me right now."
>
> I think I know if I'm doing a good job if I'm seeing light bulbs go off, and they're realizing that they have a lot more options to identify [disease] early and maybe even prevent [disease]. I just see a lot of patients for family history of [disease]—so many of them think [there is only one option for screening]. And so I think then I know I'm doing a good job.

Conversely, participants noted that their own confusion about a patient's decision can indicate a session going poorly.

> [In a successful session] I get to the point that I think I understand them, and I know that the session goes badly when I don't understand them. When I don't understand why they're deciding what they're deciding. You know, say for example, they're giving me a long list of arguments about why they should [follow a certain course of action], and then they elect to do the opposite. Or they keep on requesting a certain test or a certain procedure, and when my questioning doesn't yield an answer.
>
> When I feel like, OK, yeah, I get it, you've explained it so that I understand why you are deciding what you're deciding. I feel that I'm an effective genetic counselor because we have worked together so that I understand where they're coming from. There's a disconnect when it just doesn't make sense to me, that's when things are going badly.

Category 11. Verbalizing Intuition and Encouraging Feedback (*n*=5)

Participants noted they verbalize their thoughts, intuition or hypotheses for patients' responses. Many participants expressed the importance of monitoring patients' verbal and non verbal feedback.

> It's very intuitive. And I guess part of the mechanics of it is verbalizing one's intuition or one's assumptions, so that they can be corrected by the patient**.** Because it's equally possible that I think that I understand them, but I'm really wrong. And so a part of that process for me, is to be explicit about what I think is going on, so that I put it on the table for them to correct me, and that allows me the additional reassurance that, yeah, I really am on the right track, that I do understand them.
>
> Most of the time, I think you can tell [if the session is going well], because I might say something, "It sounds as though your concerns are X, Y and Z, or it seems like you would be interested in the genetic test," and they immediately deny that, and so clearly you haven't been picking up on the right thing.
>
> At the end [of the session] for men, sometimes you can tell by the way they offer to shake your hand and the way they want to do that and [say] a couple of words to make you realize they were there, engaged, and felt there was value.
>
> [Re: asking a patient for feedback] So, "Say back to me, just tell me what I just said to you." We had a session on Monday and we were talking about [particular] testing. And we asked the guy, "So do you understand why the results are going to come out with [description of results]?" and he was able to articulate that.

Several participants noted direct feedback from patients telling them the counseling went well.

> Sometimes they'll tell me. People will say, "You really make this understandable." Because they're kind of surprised. They're not really expecting that they can understand something so complex, so they tell me, "You make this understandable."
>
> I've had clients tell me that things are working for them, and I think that's the best gift you can get. Because when people are quiet, you don't know.

Category 12. Challenges of Unengaged Patients (*n=12*)

Arising from a question of whether there are patients with whom you work less effectively, several participant master genetic counselors said they have a harder time working with people who are not, engaged in the process, either because they are reserved or because they are just going through the motions of genetic counseling. These participants then feel less connected and less effective.

Several mentioned having a hard time with patients who are quiet. I think the other sort of people that I think about is the quiet people. You know, private people. The one's that you say, "Well, what were you hoping to talk about?" and they're like, "We don't know." Or you know, they're not giving you anything, and you're working so hard to get them to talk.

> I think I have a hard time with patients that are withdrawn and don't communicate well. Those patients are always tough for me.
>
> If somebody's at a particular state in their life where they're not very interested in reflecting or seeking or taking care of themselves or changing anything or inquiring, that's hard for me.
>
> Well, patient who don't talk. You know, obviously I talk a lot, and the patients who don't talk are very difficult for me.

> I try not to get upset, I try not to talk too much, I try to allow for silence, I try to make some connection so I can draw them out a little bit, especially ones where we're doing predictive testing or something that I really feel that I've got to know something about them.

These participants also find it more difficult to gauge their effectiveness.

> It's definitely challenging. Those are the ones where I leave the session going, "I hope this is really what they wanted to get out of it today." Because they're not going to tell you.
>
> I don't know if I'm less effective or if I just have a hard time gauging my effectiveness with people who are very reserved.

Master genetic counselors also expressed feeling less effective with "mandated" patients—those who are attending genetic counseling as a necessity for medical procedures. Participants find these clients are sometimes non responsive, and the lack of feedback makes it hard to connect.

> [One participant finds it difficult working with] people who are just going through the motions, who don't provide any feedback or any sense that they really care at all about why they're here. They're just doing it because their doctor sent them. I'm probably not as effective because we always hope for some kind of response whether it's any kind of social cue or any kind of interest or interest in relating their family history. [It's difficult when] I can't "catch" them at any point in the appointment.
>
> I guess there are people who have to go to counseling. With genetic counseling in some clinics, we're something you have to see before you go see the picture of your baby. You get a fair number of unsatisfactory interactions when people view you like these bump on the road.

Category 13. Success Can Be Ambiguous (*n=7*)

Master genetic counselors sometimes experience ambiguity in knowing whether they are doing a good job. Several participants noted that success can be difficult to gauge in genetic counseling and they offered various reasons for this difficulty. In fact,

when asked how they knew if they were doing a good job with a patient, several participant master genetic counselor responded that they don't know.

> Sometimes you don't.
>
> I think that's one of the most mysterious aspects of our job is that we don't... things can be nice and friendly on a very superficial level, but it doesn't mean we've really achieved what we hope to.
>
> So I'm not sure you always know what you're finest moments are. I think sometimes you're surprised by them.

"Feeling successful" is not the same as "being successful." Several participants noted that success is based on the client's point of view, not on the counselor feelings of success or intrinsic rewards. If doing a good job is determined from the patients' point of view and outcomes from patients' perspectives are not assessed, they have no way of knowing if sessions should be done differently.

> If you take the focus off the client, then I think you're in danger of succeeding in feeling successful, but the question is, are you really successful? Because your focus is more on your success than on the clients point of view or what they're getting out of it. Have you even asked them what they're getting out of the session?
>
> I think the reflex answer to that would be "Well when you feel good about it, when it meets this that or the other." But from the client's point of view, you don't always know.
>
> So, I don't know that I always know whether I've done a good job or not because those are my perceptions, not necessarily theirs. And I don't know that I can always translate something that seems superficially nice and good into meaning that I've done a good job
>
> Success sometimes is just about making a start, planting a seed that can grow, with effects down the road.
>
> I've had situations where I felt like it was difficult getting through to a client, and all I tried to do was make a start, and then I learned later that that start grew into something. And from the client's point of view it worked fine. I had a sense of not knowing if it was a good session or a bad session. So, when you're doing a good job with a client should be from the client's point of view.

Neither does a session need to have "a eureka moment" to be successful, as those are the exception rather than the rule.

> I guess there are those eureka moments, which somebody says, "Oh I never realized," or "That's exactly what I was thinking, "How did you know?" But those aren't the rule. Those are more the exception.
>
> Those days when you really work through a very difficult patient and the outcome is OK, that's probably a really good job, too. It might not be the fabulous bells and whistles going off, and people are writing your director and saying what a wonderful person you are. But you've affected them; you've been effective in some way [even if] you weren't able to be completely effective because of what those circumstances were.

One participant noted that sometimes what looks like skillful counseling was actually about the patient being ready.

> So I think that you have to be very cognizant of the fact that you do a really good job because it was easy to do a good job. I mean there are sometimes that you feel really good about a patient, but I don't know that that necessarily tells you that you did a really good job. Maybe it does. Probably sometimes it does, but you might feel really good about a patient when you really didn't do an outstanding and fabulous job; it was just it was an easy patient. It wasn't about anything you did or didn't do; it was just that this patient walked in primed.

Other times, it's difficult to judge "success" of an encounter when the "outcome" is bad, but unrelated to the quality of the genetic counseling.

> I don't think you always know what is a successful case, because you think, "Oh my god, this is such a terrible thing for this family." How do you measure success, when the outcome is a bad thing?
>
> When I did prenatal diagnosis, I would think, you know, this is a horrible outcome, but maybe because of me it was a little bit less horrible.

Further, expression of thanks is not always indicative of a successful session.

> I've had sessions where I didn't think they went that well the patients were very appreciative afterwards. Sometimes you think, "Oh, this is great," and then you realize later, no actually [it's not].

> The other thing that I frequently comment on is it seems like the families, when families are that pleased, it's often a situation where I don't' feel like I did anything terribly remarkable, and it's often families where I've killed myself to get services for them, and help and listen, and whatever [are not satisfied]. It's just very strange. People never cease to amaze me.
>
> Certainly clients telling you that is helpful. But you could have a client tell you that you did a great job, and you didn't. They felt good, but that's not really what they needed.

Lack of patient response or interaction makes it difficult to determine the effectiveness of a session.

> Sometimes it's really obvious that you're doing something good with a client, they say oh, they just tell you and they're not just being polite, you can see that's its genuine. But there are sometimes, they're like a damn oil painting. They're just there, they're not interacting they just have one face on, and then they walk out without saying anything. Sometimes they'll just totally surprise you, these people. They'll come back later, or word will reach you other ways, that gee, they thought that was terrific. You know, I think I didn't even chisel the concrete here! So, it's really hard for me to always know when I'm doing a good job, or I guess for that matter, a bad job.

Others noted that patients' body language can be deceiving or misinterpreted in trying to judge success.

> Sometimes people surprise me, especially like if the husband or the brother came along and they're just sitting on the side with the closed body language, not really participating, not responding to invitations to participate. And sometime at the end, all of a sudden they'll ask a really astute question, and oh my, they were listening!

Domain 11. Challenging Cases

This domain arose from two questions inviting participants to reflect on a case that was, perhaps, "not their finest moment" as a genetic counselor, and another about patients with whom they feel they are not as effective. *"Where we crashed and burned?"* clarified one participant. "Yes, exactly," replied this investigator.

These master genetic counselors openly discussed difficult encounters with patients. Most described them in detail and at length. They seemed quite comfortable in discussing their less stellar interactions with patients, their failings, challenges and related feelings.

In a very prevalent theme, most of the challenging interactions involved strong emotional presentations on the part of patients or patients' family members which often triggered equally strong emotional reactions for the master genetic counselors. Participants identified challenging patients as those who present as angry, aggressive, manipulative, or quiet. These patient behaviors trigger defensiveness, anger, feelings of inadequacy, or failure for participants. An overriding theme seemed to be that participants felt they had caused some degree of harm. As one counselor commented:

> I was trying to help, but instead I had blundered. Instead of helping the patient I had made it worse.

Many participants seemed acutely aware of their own internal reactions at the time, and upon reflection later. Several noted the incidents occurred earlier in their careers and were learning experiences for them. Others identified their own part in the interaction, or aspects of their own personalities that interact with certain difficult interactions making them more challenging for the counselor. Several participants commented that they wondered whether the patient in question had a "personality disorder."

Some participants described difficult emotional encounters as having the flavor of a defining moment or as touching on countertransference issues.

Category 1. Angry, Aggressive, or Confrontational Patients/Families (*n=10*)

Sessions with angry, aggressive or confrontational patients could be difficult for master genetic counselors participants. These types of behaviors trigger visceral reactions in master genetic counselors. Participants identified reactive feelings of protectiveness, defensiveness, anger, confusion, and failure. Participants noted they try to connect with confrontational clients—or their family members, often husbands-- but they are not always successful.

> The angry, confrontational patients, I mean, those are really the difficulty cases.
>
> Some people are just harder to reach or connect with and it may have nothing to do with you at all, but there are certainly ones that seem more confrontational or hostile, and there's not a lot you can do with it. I think that most of the time I am able to reach them. But there are a few that absolutely I don't.
>
> The group that probably I would have the most trouble with are probably people who are quite aggressive and fortunately I don't have very many. They may start off aggressive, but very quickly I can figure out what's driving it. I think I probably get somewhat protective of myself, and I probably back off a little bit. Because I'm afraid to push someone's button and afraid to have a flare up that will be hard to address.

Some participants identified their own part in the interactions as well, such as one individual who described how she attended to a family member's anger rather than to the patient.

> I had a [patient with a] very confrontational husband, actually. We have forms that everybody has to sign, and this was a husband who didn't want to sign the form. I was holding to my protocol where you just have to sign the forms, and it was just one of those things where anger mounted on both sides very quickly. He was very angry, I was getting red and angry, and his wife finally said to him, in tears, "Why do you always make everything so difficult? I'll sign the forms." And I said, "Oh, OK, good." I had been dealing with the husband; I hadn't really been dealing with the wife because she hadn't said anything. I just wanted to get through the counseling as quick as possible and did. But it was just a very difficult situation, mainly because of the husband. Very unsatisfying. On the other hand, I think this man has a personality disorder.

> The angry patients. When I think of terrible sessions, truly blowing-up sessions. Not so much on my part blowing up--actually I don't think I've even blown up at a patient. But if they get very angry with me, I find myself having very little ability to do some of that self-talk, because it's very confrontational. And in both of [my examples] it's always the dads, angry dads, which I think it's not so much the gender part of it, but sometimes I'm like, "Why are you angry? Why are you angry at me? What's making you angry?" And in retrospect, those are the questions I should have been asking [them].
>
> I have done some processing on those that didn't go well, because that is truly the opposite of who I think I am as a genetic counselor. I wish, hindsight is 20-20, I had really kind of advocated for them in their anger, versus feeling the need to defend myself and the field of genetic counseling. You can just try to remember that anger comes from fear. I think it's just such a visceral reaction that happens before you're able to process in a more intellectual way.

Many participants described finding and empathizing with the emotion underlying a patient or family member's presentation of anger as one way to address challenging situations.

> One I really remember would be more of a challenging case. And it was an angry husband. He hadn't come along for the first visit. So knew nothing, but he sure thought he did. He kept quoting obscure studies--just his need to have some control.
>
> If I was a rookie counselor, it would have been like playing tennis. I would have seen those as test balls that it was my job to hit back across the net. I would have felt the need to factually address each of these studies he was bringing. As a more developed counselors I could see right past the tennis match to what was really going on. I could see, Oh my gosh! He feels so out of control, so powerless. This is like all he can do is lob these tennis balls at me to try to make himself useful. It was really interesting.

Another counselor set a boundary on an angry phone call from a patient.

> It's just they're angry and that's how they're handling it, and they're belittling me! I mean severely--not just in a trivial sense--but somebody who's blaming you for things you didn't do. And it may be especially [disconcerting for the genetic counselor] if it's a client who you've really tried to help a lot. So I just told the client very calmly that I wasn't going to discuss it with them right away, that I would call them back, and give them time to calm down. So then when I called her back she had calmed down, and she apologized.

Several participants talked about using a word or phrase that unintentionally triggered a huge emotional reaction in a patient. One participant talked about doing grief work with an adolescent, whom she very deeply wanted to help despite some ambiguity about how best to do so. The participant unintentionally used a word that triggered a strong emotional response from the patient that lead to a rupture in the relationship, and feelings of failure on the counselor's part.

In retrospect the participant viewed this situation as "a great example of not knowing enough about your client and how they make sense of things" as well as a professional growth point for herself in understanding her own strong need to help the patient.

> I was doing a lot of work trying to understand what she wanted at this point. So I said something like, "You know this is not a circumstance where we would think there is something genetic. You have a slightly increased risk because of your [relative's] illness. But this is just random bad luck." And she went berserk! She said, "None of this is luck! It has nothing to do with luck! Bad luck, good luck! Don't talk to me about luck!" She was so angry. Obviously it wasn't hard to understand why she was angry, but I just stepped in it…
>
> And then she started to talk. She went on about the word I had used was completely not in keeping about how she felt about things. And I think what was really hard is that she didn't want to talk to me anymore, and we weren't done. I basically spent another hour saying that I was wrong and I made a presumption without knowing her well enough. I asked if she'd be willing to work with me and do a better job, and start over. It was really, really hard work. It was a hard negotiation…
>
> …And I knew in my heart of hearts that she wasn't really mad at me, I had made a mistake, but she was really mad about her circumstances, as she should be. But it felt very personal, and it felt like I had failed, and it felt like I had done a bad job.

Through supervision, the participant identified her own countertransference issues around needing to reassure the patient.

> I have a professional supervision group myself, and I did a lot of work around that case over the years because it was so multilayered for me. So many of my own issues of failing this young girl, and needing to perform at a higher standard. It was very, very hard. I mean she was the most loveable young lady and […] knowing that I couldn't reassure her about her [current situation] which is all she cares about right now. There were just so many multiple layers…
>
> I couldn't bear that I had done such a bad job. So, it was very, very intense. And I liked her. She deserved to have a good session. I really care a lot about her, and I cared to try to help her through a really, really, really horrible time in her life. And then this whole issue of not doing my best job, that's always very hard for me. The part I was proud of was that I didn't give up.

Category 2. Patients' Strong Reactions to Bad or Ambiguous News (*n=3*)

Patients' aggressive physical and emotional reactions to bad news are difficult for participants, despite the fact that they understand why patients react that way. Some participants talked about these types of reactions when delivering bad news.

> I learned that dad had had a sister who had [a genetic disorder] and died. As part of the session I pointed out that we really ought to test the baby, because this was genetic and it's possible [the baby was affected]. When I met with the family to tell them that this child indeed also had [the disorder] dad literally stood up, threw a chair across the room and walked out. And he was clearly at a point, where he couldn't [handle it]; this was too much already. This was more than he could handle. But I think that was just an information thing, so that really didn't have much to do with anything I did.
>
> I was informing a couple they had a diagnosis prenatally of Down syndrome, and I remember during the session, these people, especially the woman, had a fairly dramatic personality, and I showed her a picture of a baby with Down syndrome, she was asking lots of questions about what it was,. And she stormed out of my office. Slammed the door, stormed out of the clinic! And her husband was, just as stunned… I was in total panic, nothing like this had ever happened to me before … and I'm trying to think, "Well, what should I do?"… And maybe after 15 minutes she came back in and she gave me this whole big lecture about how I was insensitive to women and I should never do something like that and I thought, "Well, I'm not going to fight with you lady, sure, maybe I was insensitive, I don't know. "But I just let her get it all out, and then we went on.

Having reflected on the incident the participant cited learning.

> I have to be careful when I give information to patients although sometimes patients are going to act out and that's the way it is. It doesn't mean I'm necessarily bad; some people are "acter-outers."

Category 3. "Button-pushers" (*n=6*)

Several participants reported challenges in working with people they view as manipulative.

> I have a difficult time with patients who manipulate and who try to get more out of the system. We don't like giving preferential treatment to the person who complains the loudest, but I particularly hate when patients push and push and push, until you go, "What the hell, I'll give you an appointment for tomorrow!"So I have trouble, I struggle being empathetic with those kinds of patients.

> I was unable to move forward with any of the information because anything I tried to bring forward was kind of met with a stone wall. It was almost like she was there for the purpose of creating a problem that didn't exist. It was very difficult because she was very much a button-pusher. As far as I can tell, that may have been her goal, to actually create a scene. I did not lose my temper, but what I finally [said] was, "You know, I don't think I can give you what you need, but I would like to refer you to a different genetic counselor. There are lots of genetic counselors in the city, and I just don't think I can meet your needs." And then she totally shut up and behaved.

A few participants connected their reactions to feeling manipulated to their upbringing or other parts of their past.

> I felt really manipulated, I was very angry. I cannot stand being manipulated, and I can spot it a mile away. It is very much one of my buttons, so someone who is trying to "bleep" with me, I know it, even if they don't realize it. It's probably back to family issues as a child. It's just one of the things I have a really hard time managing when I feel manipulated.

> I've lost my temper with clients, over the phone always, when somebody's trying to manipulate me. It's only occasionally happened, but it's definitely not a finer moment. I think that's just part of my life experience, it's always bugged me.

> The patients that drive [me] crazy-- there are some people who are so dependent on you that you have to do every single thing for them. "Hey, I'm trying to empower you, don't make me talk to your family, and don't make me do every single thing for you in dealing with your insurance. Take control yourself here, a little bit." Sometimes it's a struggle [to encourage independence], and I think,

> "No, I can't do that for you, sorry." Sometimes they'll step up to the plate, and sometimes they'll find someone else who will help them.

Category 4. Chaotic Sessions (*n=4*)

A few participants described difficult sessions in which there was so much going on that they had difficulty tracking it all. They experienced their own strong internal responses, and variously felt unable to read the patient, unclear about the families' goals, and disconnected. For example, one participant described a parent's vacillating emotional presentation in a session that was already chaotic with misbehaving children, in a busy clinic, with insufficient time. This counselor understood the father was in denial about test results, but his emotional reaction was shifting quickly from aggression, to accusation, to apology. The counselor felt misquoted, personally attacked, manipulated and frustrated.

> I do feel that I couldn't quite shift fast enough. He was going through those various presentations, so quickly that I didn't know how to keep up with him. I didn't know what would be coming at me next. And because he misquoted things that I had said, I felt kind of personally attacked. At one point, probably about halfway through, I felt like I disconnected. I just I thought, "I can't invest anymore because I don't know where he's coming from, and I'm not going to be able to satisfy him."
>
> And I felt like I disconnected and I shouldn't have. But I just couldn't summon up the energy to meet their needs, and I couldn't even figure out what their needs were because they were changing almost momentarily on me.
>
> I felt uncomfortable. Even though I felt they were being quite manipulative, I felt like I didn't rise to the occasion. I just allowed them to push my buttons and then shut down after I tried a couple of different routes to try to normalize, or try to validate their concerns, or try to see what we can do to help. I just shut down.

Another participant concurred that it can be difficult working with "patients that are all over the map" emotionally. She described such a situation of also feeling personally attacked.

> You know, I specifically remember a patient who went from loving me, to hating me, to screaming at me, to kissing me all in one session.[It got to the point that] my goal was, "Get her out of my office even if I have to offer a test she doesn't need." I was so uncomfortable that I felt like I was coming out of my skin. I literally felt sick to my stomach with this dread of "Oh my god. What's going to come out of her mouth next?" And feeling very personally attacked.
>
> And then afterwards feeling not in control about that. That was not a good session. I don't know how I could have done better. I don't even know if I was that introspective. I think it just sort of that [feeling of], "Run!" [chuckles]

Another participant described a different kind of chaotic session in which "the patient got lost in the shuffle" as she tried to meet the needs of several generations of family members. Several family members attended a session planned for one older family member to decide about testing. The other family members' agendas took the focus, and the counselor described "trying to please everyone [and ending] up pleasing no one."

> I just walked into this family soap opera, where the [adult child] was there, the [child] was I think in his 30s, had not been tested for the [genetic concerns]. So the mother was worried about [the child], who was really absolutely adamant not to be tested. The mother was furious that I did not just pin him down and test him. In the meantime there is this older [family member] who is very sick, and I tried to kind of bounce back and forth and I thought I was doing a pretty good job.

But one family member ended up very angry and pushy.

> And I think I should have just nipped that in the bud, and focused on the patient. It just got really muddled trying to pay attention to everybody and make everybody feels as though they got what they wanted. So nobody got what they wanted. Everybody was upset, and I needed to wrap things up. I think what I should have done, is to say, "You know, I understand that there's this whole issue of whether [the adult child] wants to be tested or not, but that is a whole separate

> issue. Why don't we put that on the shelf, or let me call you later or something. It was of those situations where the patient got lost in the shuffle.

Category 5. "Blunders" and Lack of Experience (*n=4*)

A few participants noted their difficult sessions occurred because of their own "blunders," inexperience, or naivety.

> The ones that I'm not as effective with probably are teenagers. I have a lack of experience dealing with teenagers.

Poor choice of words in working with grieving families was difficult for a couple of participants who had little personal experience with grief.

> I was truly trying to be helpful and understanding of their grief at that point, but clearly was naive as to what really transpires. And if anything it just made them angry and it was part of my naiveté. It was a very worthwhile lesson, but unfortunately that was at the expense of somebody else's feelings.

Miscommunications with patients led to difficult encounters for other participants. One counselor talked about calling a patient to discuss an autopsy report when the patient had informed others on the health care team that she did not want an autopsy.

> Neither she nor I realized she thought she was telling the whole team that she didn't want an autopsy, and I thought she was just mentioning it to me. Because in the hospital they're also supposed to tell the doctor and anyone else within earshot that they don't want an autopsy; autopsy is the default. So when I received the report a number of weeks later I phoned her and said, "So I have the results of the autopsy, and she absolutely lost it, "I was reaching closure and you have just destroyed all the work that I've done in the last six weeks!" I just felt really badly.

Category 6. Ambiguity (*n=1*)

Some participants felt they had not helped in situations that involved ambiguous information. Although driven by circumstances, such sessions can be unsatisfying for

both the patient and the master genetic counselors. One participant noted the difficulty in helping patients deal with ambiguous test results.

> I feel like with those gray, uncertain things. It could be really, really bad, or it could be just fine, and there's no way to know. And having some people who just can't accept that. I'd gotten to the point I just don't know if I'm being helpful. I've exhausted my toolbox skill set and I don't have them to a point where they want to be. With the most difficult cases, that I just sort of sense that I've done everything I can do and they just can't accept it. I can't tell them whether it's good or bad. , it just sort of feels like you're in a frustrating dead-end. You sort of exhaust every possibility you've got trying to help them come to peace with that.

Category 7. Personality Styles (*n=3*)

Other participants said they sometimes feel less effective with patients whose personality style is different from their own.

> My personality is very, very forward. You can see on my face what I'm thinking most of the time; I'm not very good at disguising that. So I try to be upfront, forward and engaged. People that have the opposite personality style, people who don't reveal themselves easily, it's hard for me to read or engage. So I also feel less effective, but I don't know if I'm less effective or if I just have a harder time gauging my effectiveness.
>
> Yeah, definitely –people who don't talk. It makes it really hard. I wouldn't say I'm afraid of them, but I have to really tone myself down and take a slower approach, try to work with them to try to figure out ways that they can convey how they're thinking or feeling. I'm having a hard time reading them. But definitely I'm somebody who thrives on messages. And I can get a lot from body language and things and circumstances, but still it really helps if people talk.
>
> I guess I'm very, very linear, which is probably true for most genetic counselors, and I think sometimes clients who are more creative thinkers jump around a lot are more challenging for me.

Category 8. Reflecting on Difficult Cases (*n=7*)

During their interviews, several participants were very reflective about their challenging cases. Some encouraged reflection on challenging cases as a means of

counselor development. Reflecting on cases can help genetic counselors develop stronger skills in hearing patients' underlying messages. Sometimes those messages directed toward the counselor may carry a kernel of truth that is uncomfortable for the genetic counselors to hear.

> Well, sometimes we hear feedback, or we get messages from patients that are difficult to take, difficult to hear because we're trying to help. And if patients are angry for one reason or another, or sometimes they tell us they we're not good in one way or another. And while certainly a lot of those messages reflect patients being upset with the news, the whole situation they have to deal with, sometimes there may be an element of truth buried in that [message that] we shouldn't be afraid to look at and let in.

> On-going reflection can also reinforce that over all, most genetic counseling cases are successful rather than extremely challenging. You know we always remember our faulty ones, [more than] the positive stuff. You know, they tend to stick to your ribs a little bit longer. We all play the little video tape in our head over and over again when we screw up. But you never play over the video tape when you were successful. You come away with a little smile, and you think you're clever, but you don't play it over and over.

Several expressed the benefits of consultation, supervision or debriefing with others. Some noted that it took some time to process their most challenging cases.

> I've reflected on it a fair bit, and reflected on it with the geneticist who's actually very compassionate; she was in for part of the session. She just said, "You know, there are just some families that are like that. They're in denial or they want things their way and that's the way it goes."

Some noted that not every case will be as successful as they might like, and discussed the importance of taking some challenging cases in stride.

> [If you] see 100 people in a row and you don't feel like you're engaging, then something isn't right. [But] specific instances of things going really crappy are either a) the patient's kind of nuts, or b) you're having a really bad day, or c) just the circumstances are so crappy that you can't help it. So I'd say those are less teachable than just sort of recognizing in the over and over and over again what's not going right. If you try to fix those weird, real dramatic situations, well, they're weird because they're sort of exceptional.

> The cases where you really want to do a good job on are the cases where you don't connect with patients. That's where you need to put more work into it. But then you also need to be able to say, "The outcome still wasn't good, but I did everything that I knew how to do."

Others noted that difficult cases present an opportunity:

for learning…

> So, I frequently tell students "You learn your best lessons about how to handle situations either when you observe or you yourself don't do very well."

…for empathy and self-awareness...

> And just say, you know, this is the person, and really, you should feel for them. Because would you rather be you, being the recipient of all this? Or would you rather be this person, who this is their life every day?

…and setting boundaries …

> I wasn't going to see him

> Wait, you don't [get to] do that!

…and choosing battles.

> And maybe recognizing those things that happen, that patients blow up at you, scream at you-- something if it happens once every two years…vs. the people that you see day after day after day, and things go pretty well, but there's something about it--fixing that seems more worth your time.

Domain 12. Art Vs Science

These results arose from responses to a question asking how much of genetic counseling is an art versus how much is a science. "Oh man! That's a loaded question!" noted one participant.

Most participants reported that genetic counseling is a combination of art and science, with many of those conceptualizing it evenly split between the two realms. Otherwise, smaller but similar numbers of participants consider genetic counseling to be

either mostly an art, or mostly a science. Those who see it mostly as a science do so to a strong degree, saying it is 70 to 85 percent science.

Participants described the art of genetic counseling as including intuition and people-oriented personality traits. Interestingly, counseling skills and the counseling process, were considered art by some participants and considered science by others. This debate seemed centered on whether or not such skills can be taught. Some noted that having a predisposition toward people skills is helpful, while other said that counseling skills can be taught. Semantics pertaining to the word "art" were bothersome to some science-inclined participants, and it was not defined for them in this context.

Aspects of the science side included scientific information, scientific method, and basing decision on evidence. The science part of genetic counseling was generally considered "foundational." Some considered "information" to be "science." Others expressed concern about a trend toward greater emphasis on "information provision" or about what they regarded as the "routine nature" of some genetic counseling.

Whether they viewed genetic counseling as largely art, largely science or both, participants seemed to agree that exemplary genetic counseling is individualized.

Category 1. Genetic Counseling as a Blend of Art and Science (*n=8*)

Some master genetic counselors consider genetic counseling to be a balance of both art and science. In this view, the science is foundational, while the art of genetic counseling is "finding your voice in how you do it." For them, perhaps, the content is the "science" while the process represents the "art".

> You can't do what we do without learning what we learn in school and through articles and conferences. I think that's all the science of it. And that's very important. But I think how we do our job is an art. Even in the most traditional

> sense of a genetic counseling session, there are infinite ways to accomplish what you need to accomplish. And I think the art is to determine how you are most effective.

> It definitely is an art, there's no question about it. I mean, the reason I went into it originally was that it combined everything I love to do, which was talking to people, but it had to have the substance, it had to have the science, because I'm really a scientist at heart. And that's what really turns me on about it.

> It's a combination of both. It's just like medicine. What we try to explain to our patients, that is an art.

> I guess you can't make a good meal with lousy ingredients as they say. So I think you have to start out with the art, but it's meaningless without the science, without the skill. Skill might be a better word than "art" in this sense. Your skill allows you to use your art. I mean, there's no way anybody can be prepared for everything that's going to happen in their genetic counseling sessions. People are just full of surprises.

Some regard the "art" part of genetic counseling as encompassing the counseling components, including communication, digging beyond the surface, sorting out and understanding the layers, motivations, reactions to information, and emotions.

> The art, probably, comes more in terms of how we apply [the science] to real life.

> The counseling piece is the art, the communication and sorting out, "Alright this person's saying this, but what's motivating them, or how are they dealing with the information I'm giving them? Do they get it? Are they upset by it? Why are they upset by it?" And sort of digging deeper into that.

The "human side," such as genuinely expressing caring, may be part of the art.

> I think that there's a humanness [her emphasis] that you might see in any health care provider or in any person where you just sense that they're bringing a different element of caring. And I suspect that that's more of the art. How one might project that might be more of an art, because it has to be real. I mean, our families are very good at sniffing out anything that's false or supercilious, and so I think that people who try to do that aren't very successful, and that might be the art.

Responding to patients' individual needs also involves the "art" side. Participants related this type of responding to flexibility, listening to emotions, and being open-

minded. The art involves discerning what is salient to patients, and sometimes what is salient is information.

> Well, I actually [thought] 50-50, and then I [thought], "It depends on the day." Some days it's all art! Some days it needs to be more science. I think it's really very patient-dependent…
>
> …There are some [patients] who come in and they are very together and they have figured out their emotional issues and they've addressed them and they're open about that. I think the art part [then] is listening to that…
>
> …You adapt your agenda and personalize it to the person or the patient that's in front of you.

Skillful use of counseling skills may imply artfulness.

> There's definitely an art to using [psychosocial skills].
>
> You're counseling a patient who is an engineer and all they think is, "OK, you're telling me numbers, and those numbers are what are important to me. All this other stuff you're saying is not important to me". So it really is providing that [information] in the right way for the person in front of you.

One participant took a larger view of the art of genetic counseling, extending that view beyond patient interaction and relating it to expanding the profession.

> I know you're talking more specifically about patient and clinical interactions, but, you know, this may not be a patient, this may be somebody else. This may be a director of a private practice that you're trying to convince to hire you, so adapting your agenda to what things are important to them, and so that's what I think the art is.

Although there might be a tendency to equate "art" with psychosocial skills, one participant pointed out that the study and teaching of counseling skills is also a science.

> I was going to say that psychosocial stuff tends to fall more in the art area, but I don't think that's true. Psychosocial information and techniques also fall under the science realm—we can study them, we can teach them, we can dissect skills. But there's also definitely an art to using them. So, I don't know, I think they're equally important.

Another noted that she thinks it's possible to learn the "art" part of genetic counseling, but that some underlying skills or traits are helpful in that regard.

> I think that the art is something that people can learn. I think it helps to have some level of communication skills, awareness and that piece of it before hand.

Several expressed that the art carries the functionality of the science beyond competency to more master levels.

> I think the science of what we do is important. It's just that it's much easier to focus on that. So people who achieve basic competency usually get that. Although not always.
>
> I think probably being a master [genetic counselor], being really good at it, is somewhat the art. You know, I think the science is doing it functionally.
>
> The base has to be strong …that's the science of it, that's the structure. But then the art of it is, how creative do you get?

Perhaps it's an integration of art and science.

> I guess the art versus science…in a way [genetic counseling is] kind of [a connection of] the two.

Category 2. Genetic Counseling as Primarily Science (*n=4*)

Several of those who viewed genetic counseling as mostly a science also self-identified as scientists. They contended that solid genetic counseling is founded in solid science.

> I have a very biological view of life, and the scientific method… Doing really good literature searches [is very important]. Don't take [just] one paper. [If] there're 20 papers out there, the answer's going to be the central tendency, most likely. So understanding that kind of stuff. There's a whole lot of science to what we do. And it has to be good science.
>
> I guess I think that probably 80-85 percent of [genetic counseling] is science. I think a lot of it is a science. I think there are many skills that one needs to be a

really solid genetic counselor, to be a great genetic counselor. I think that it's more of a science than it is an art.

Another participant also viewed a larger percentage of genetic counseling as science.

I think maybe the first 70 percent of it is a lot of science.

Like a few others, she included basic counseling skills as well as information within her realm of science.

I mean science in terms of how do you manage clients, how do you talk to people, basic empathy, and that level. How do you make people feel welcome and comfortable and how do you know the information? And probably if you've mastered the science of it all, you could probably be a perfectly functional and empathetic and nice counselor who does the job. Probably the last 20-30% of it is how do you really do it as an art, do it well. Probably half my patients I see it's the science. I've got six [patients with similar issues] on the schedule and we'll see them all today.

I think there needs to be lots of interviewing and assessment about where people are coming from in order to best meet clients' needs. I guess because I'm a scientist, I still want to say that that's more of a science. I mean I can teach people how to do that.

I think [genetic counseling] needs to be based on evidence, so that's to state my bias. I would claim that because I can teach it and see people respond to the ways I choose to teach it, that it's more of a science, but I don't think it's formulaic in any way shape or form. Saying it's an art to me sort of sounds like you go in and you imagine it, and you feel it, and you sense it, and you do it. And I can't live with that, because I can't teach somebody how to do that. So I guess I think of it more as a science.

Science-oriented participants viewed the science as paramount in serving patients' needs through thorough assessment. Context is necessary to know what information to provide and how to help with decisions. These participants stressed that when "science" is equated with "information giver," patients' needs are not met.

One of the things I worry that genetic counseling doesn't do more of, is figure out who the client is in front of you in every way shape and form, not just how their family has been affected by a condition or why they're at risk. But how they learn, what's important to them, their basic values and beliefs. Without that you

can't supply information or help them make decisions or help them adapt to a circumstance. I think there's too much similarity in what's offered from one client to the next, without knowing whether or not it's a good match or a good fit.

But I think that unfortunately what I see, is the trend, is that it's becoming, it's the science. It's that piece of it, it's an "information giver" as much as anything else. Someone to go over the consent form and get that signed and arrange the blood draw. Almost that information giver, and the logistics person, and the administrative stuff.

Category 3. Genetic Counseling as Primarily Art (*n=4*)

A few participants indicated they viewed genetic counseling as mostly art. One participant taking this view referred to the importance of "emotional intelligence" and considered genetic counselor' ability to read people to be intuitive.

I think it more an art than a science. I think it's very much based on intuition, and the ability to read people, and understand their moods and their anxieties. So I think it depends much more on emotional intelligence than it does on "book" intelligence. Certainly the product is derived from book intelligence, but how we are perceived by patients as being helpful or not helpful I think is much more the art side of it. And how well we can understand our patients

The question for some, again, seemed to be whether counseling skills can be taught.

My take is it's largely an art. Sort of with the thinking that a group of students can all have the same material, all have the same rotation, they can all end up with different aptitudes. In effect it may be more personality. The education part of it, I'm thinking, is the science. How to go about it, class, what you're taught, the didactic part of it is the science. So beyond that, once you have that, how you take that and go with it is largely personality.

I think a lot of people will go into the field and I think you see this with students– and I remember doing it as well—like, "OK, this isn't a science! Well, crap, now what do I do?" I have to put down my pictures of chromosomes and talk with the patient. So there's a safety in the science of genetic counseling, but I think [the art or human side] is a big part of genetic counseling that is going to be more fulfilling, at least to me.

The stuff we do is very complicated scientifically. Anybody with a certain level of intelligence can learn this stuff. It's actually doing it that's the hard part. Dealing with people's problems is the hard part.

Recognizing what information to leave in and what to leave out according to the particular patient's situation reflects the art.

> I think so much of it is an art, which is why it makes it so hard to teach, you know**?** I can maybe teach the model of genetic counseling that I value. [Students] prep for cases, and, yes, you have to know all this information on your outline. But how do you teach what piece of that outline you actually need to let go, and what are the pieces you are really going to need for sessions, and how do you assess that? I think that is an art.
>
> So I think there's certainly for many of the family's I see, "genetic counseling," that phrase is a misnomer. It's genetic information, and that's really all they want from you, and they don't want to delve, they don't want to address things like "Do we want to have another baby, and what would it mean to us if this baby had these problems, and how are we going to cope with this baby. ?" But when people do want to go there, that's more art than science.
>
> There's some techniques in there, but just cause the book says this is where this phrase is supposed to work, it doesn't always work there. You're going to have to almost intuitively know what it is you should have been saying. So yeah, I think there's a fair amount of art in this, once you get done discussing the science.

Domain 13. What Does "Psychosocial" Mean in Genetic Counseling?

The master genetic counselor participants held varying perceptions of what is included in the "psychosocial" aspects of their work. Some described an encompassing view that "all genetic counseling is psychosocial." They contended that even the informational components of genetic counseling are psychosocial in nature. Others offered more delimited views, that the psychosocial pieces of genetic counseling include "everything that is not educational." The difference seems to be how holistically the participants view the genetic counseling encounter and whether or not they perceive genetic information provision as a psychosocial process.

This theme arose from a question asking participants what they think is meant by the "psychosocial" aspect of genetic counseling and how they might address it in sessions.

Category 1. A Broad Range of Definitions (*n=15*)

Every participant answered this question, and they all reported viewing "psychosocial" as pertaining to the context of the patient's life, emotions, thoughts, relationships, and responses to genetic issues. They varied however, in how they expressed this perspective. For instance, although most participants easily provided examples from their work, some struggled with articulating a concise definition of what they think is meant by the psychosocial aspects. Some participants' definitions were vague, whereas others' were more specific.

Taking a broad and holistic view, some participants viewed *all* genetic counseling as psychosocial.

> Well, I think I really have to go back to my training. I graduated [when the field was beginning] when there was much less genetics known, so we had a lot of time to talk about psychosocial issues. I learned that it has to be a very integrated part. So I don't look at it as an aspect. If it's an aspect it's very interwoven.
>
> You know, everything is psychosocial. We're psychological creatures, so even when we're hiding behind a bunch of numbers, we're doing it for psychological reasons. How we present and interpret those numbers is psychological. Everything is psychosocial in genetic counseling. I think the hardest part to realize is that even when you're doing education it's still psychosocial.
>
> I think at the very basic level, recognizing that there's more than just communication of information going on. That this information has fairly profound effects on people's relationships with their family, and their spouses, and their friends. And often the information is potentially some of the most devastating information that they'll ever get. So I think [psychosocial means] recognizing sort of the emotional weight of the information.

One participant noted that both the genetic counselor's and the patient's biases, psychological make-up, social contexts and emotions interact within a genetic counseling session.

> What you're telling [patients] is to some extent reflecting your biases. How they're interpreting it is obviously going to be tilted to their psychological makeup. How they use the information is going to be determined by their psychological and social situation, so there's not anything that we do [that isn't psychosocial]. We're not, as we say, machines. We're not little logical automatons that make these perfectly rational decisions. We've got this sort of emotional [response] bouncing around in what we do, and it's determined by our psychology.

Concurring that all genetic counseling is psychological, another participant took exception to the word "psychosocial." This participant preferred to discuss genetic counseling as "psychological" and regarded meaning and relevance of the information to the patient as paramount.

> I hate that word. It just makes me crazy. So I talk about the fact that genetic counseling is educational, that we provide information, and it's psychological. And it's psychological because it's the importance—meaning relevance-- and the use of that information that is most important. And I think it far dwarfs the genetic facts.
>
> I think it's all about who [patients] are, how they think, how they learn, what they value, what they need, what they're seeking, how they make decisions, and that's all psychological! People make meaning of the information we give them [for] all sorts of reasons that make sense to them that don't necessarily make sense to us. So I think the psychological part of what we do is the essence of what we do. It should be the essence of what we do. And the information itself is dwarfed, and should be dwarfed, by that. So I think all of genetic counseling is psychological counseling; it's just with a genetics lens.

Some participants discussed the "subtle" aspects of psychosocial counseling in terms of learning more about their families or patients and assessing what information patients are taking in.

I think the psychosocial aspect of genetic counseling is very subtle. …For example, there are definitely those counseling cases where you're centered around decision-making, and just facilitating difference of opinion [among family members] and those types of things. But I would still say, you're still have a psychosocial genetic counseling session by listening and providing support. Even the context of something as simple as a family history, can be very psychosocial if you are able to listen to some of the things that patients are telling you about tragedies in their lives. And that oftentimes will tell you about the environment that they grew up in and the sort of informational as well as emotional support that they need.

I think you have to be able to assess where the patient is and what they're hearing and what they're unable to hear. What you might be able to do differently so that things they need to hear they can hear. And I think that there are a lot of things that have to be taken into consideration, and they range from what's this person's educational level to who else is in the room.

Other participants distinguished psychosocial aspects of genetic counseling as the "nonscientific, nongenetic" or noneducational part of genetic counseling.

I think [psychosocial genetic counseling] refers to the nonscientific, nongenetic components of genetic counseling. It's where you're putting [the patient's] situation into context, where you can take onboard what they tell you about their life situation, their goals and aspirations, their fears, their religion, their family structure, their hopes-- where you can take all of those other dimensions and work within that framework to help the patient move forward.

I think it's almost everything beyond the educative portion. I think it's all of the emotions and the ethical issues and the cultural issues, and it's the "people" issues beyond the science, beyond understanding the concepts. It's the interaction, the human interactions—and everything it takes to have a truly effective dialogue where people are able to learn, where families are able to learn and move forward.

First off I think it's the decision-making opportunity that you get to after you present the information. Eliciting concerns that patients have… And trying to develop a climate of comfort for the patient. And lastly, trying to empower the patient to face either the decision or the situation. Those are the things I think of on the psychosocial side of my counseling.

Other participants focused their view more specifically on emotional concerns and relationships.

To me the psychosocial aspect of genetic counseling is the emotional impact that genetic testing and having a disease in your family can have.

Another participant considered the concept of psychosocial genetic counseling in terms of its root words. She noted the impact of a family's beliefs, such as those based on culture, ethics, religion, and values, that come into play in facing genetic decisions. In emotionally difficult circumstances, patients' may have the added stress of their usual support systems being unavailable to them, compounded with dissonant existential issues about their own beliefs.

> [For this question] I sort of divided it into the psychological and social. We see a lot of very religious people… people with a very strong faith. [Then] something's happening that they can only perceive as God's will, because it's the only way they can get through it. But they now have some options to make decisions… that have profound social implications for them, should members of their congregation realize that's what they did. So, sometimes I have conversations with people about the social aspects of "What if I use prenatal diagnosis? What if I terminate a pregnancy? What will my friends and neighbors and family think about? And that's obviously tied into the psychological issue of how am I going to approach this? Who am I going to share this information with? How am I going to deal with what my whole life I have been told is something I should never do, when in fact, here I am and suddenly the circumstances have changed?"
>
> As well as the family who says, "We know we have a high risk, we're going to try again, and everybody in our family and our friends think we're crazy because we've got this substantial risk of another baby with problems." So it's very intertwined, the bottom line is you've got to chip away at both sides of it in working with families.

Category 2. Psychosocial Perspective is Essential (*n*=7)

Beyond differences in their definitions of the concept, the participants agreed that the psychosocial part of genetic counseling is essential to understanding a patient or family. In fact, one participant suggested it is skills in the psychosocial realm that differentiate master genetic counselors from competent genetic counselors.

> I think, master genetic counselors are much more likely to hone their psychosocial skills than counselors who only achieve basic competency…So I think in practice, it's really psychosocial skills that tend to set apart the counselor that gets beyond basic competency.

In their work with families, participants identified many pieces they consider psychosocial components of genetic counseling and their import for the patient, the family, and the genetic counseling process. For example one participant noted that concerns of a patient who is an only child could be different than those of a family of siblings, or parents vs. nonparents.

> I ask about what's your social situation, what's your financial situation, who do you live with, what's your relationship status, all of those kinds of things. The psychosocial issues for someone who's an only child who doesn't have any kids are very different for somebody who does have kids.

Another participant discussed the interactions among family relationships, communication dynamics, generational concerns, emotions, and identity development that can occur within genetic counseling. Her description also identifies the added interaction of the impact of genetic counselors' values and decisions in addressing a family's concerns.

> I often kick parents out. Even with adult children, I kick parents out of the session because I know both from my practice and from being a mother and from being a daughter that everybody's always trying to protect everybody else, and sometimes it's just OK to have feelings. [I explained to one patient] "It's ok for your mom to feel guilty. That's a part of her integrating [genetic issues] into who she is. And you don't need to worry about her feeling guilty. Because that's a normal part of what she has to work though. No need to protect your mother." That was probably a great relief to this patient to really understand that they're just feelings.

Another talked about the meaning and relevance of information to the families with whom they work.

> What does and doesn't really matter in these people's lives in terms of living a good life and quality of life? And it's not necessarily understanding the nucleotides involved; it's more the relationships and the support they have.

Some participants noted the process they employ around psychosocial issues. For instance, active assessment of emotions during a session can provide access to how

people process information, dynamics behind family stories, additional emotions and the impact each of those might have on decisions, decision-making, and coping.

> I think that [psychosocial issues] have to do with a lot of how people are processing the information that you're giving them. What it's like for them to sort of tell their story about [genetic issues] in the family, so [I] assess the emotions through the session and also in the making decisions piece of it - Should I have the genetic test or not? If I have the genetic test should I get the results? Now what do I do?

The impact of psychosocial issues on genetic counseling or genetic concerns can be quite subtle, and discerning those effects can take attuned and skilled assessment. A participant talked about the impact of a child's test results for one mother. Because the genetic counselor knew the mother's history, she could better understand the mother's reaction to a diagnosis.

> I had a young woman recently, and I took her family history, and how she was able to get through [particular family problems] is amazing. …. So I think if you can take that and use it and assess that very subtle piece of just taking the family history, in how you're going to work with this family. I think that's psychosocial genetic counseling

Participants noted that how patients think and learn, how they interpret and use information, their reactions to information, decision-making, and what they do after making a decision, belong in the psychosocial realm. Reactions are not always expected or logical, but they can affect coping. Several participants talked about the importance of recognizing the subtext and its impact on the session (i.e., attunement to what is hovering subtly under the surface) that might need attention.

> Recognizing underlying or unspoken things that may be going on that may be impacting the conversation. You're trying to talk about [the disease] but really, the couple's fighting about something else. So just recognizing there's some other subtext. Recognizing what you have to recognize to accomplish what the goals are in the session.

> I ask about any previous diagnosis of anxiety or depression or other kind of mental health issues.

Another participant described how old family issues can resurface in genetic counseling in talking about the reaction of a patient who had tested positive for a genetic issue and was advocating for other family members to be tested.

> One of [her] first challenges was getting her sister in. And of course we all want [the sister's] test to be negative. If that test does come back negative it isn't necessarily all relief and joy that happens. Because people are so much more complicated than that. And sure enough, the test was negative, which was what we all wanted. If we had magic wands, that's how it would end up. The instant after that first relief [the sibling] absolutely broke down in tears, and it was the survivor guilt of "What have I done to deserve not having that?"
>
> And surprisingly the [patient who had so strongly encouraged her sister] later had a reaction. She said, "You know, I'm so glad we talked about it ahead of time. I'm not surprised. She got her [schooling] paid for, she is the pretty one…" All these things that are [little issues] in a family that have been dealt with, bubble up like little bubbles in the fizzy water. Well, we have to let some of those bubbles out and pop, and the rest of them, put the lid back on.

This participant also described the importance of the process and of rapport in addressing psychosocial issues.

> I think there are a couple aspects to it. One is there's an interactive aspect and observational aspect. So interactive-- that's like the personal connectedness that can occur, that's like the rapport, working together, to solve something…
>
> …Then the observational-- that's the little nuances, or a little bit of gentle prodding, or careful observation, that helps me see what might be under the surface that could need attention. So I think the psychosocial aspects are two different parts of it. One is that rapport and the other is what have the effects of this been on this family and this person? What about that might be important for her decision today? And what might be there that might need more attention**?**

And finally, some participants identified genetic counselor components of the interaction, including countertransference and recognition of competency boundaries.

> [Psychosocial work] has to do with people's reactions to situations, and then your reaction as a counselor to their reaction.

A couple of participants made a distinction between psychosocial genetic counseling and psychotherapy.

> It would be hard work to do if you didn't understand the genetics, but I think it's psychological counseling. What's different is, it's not psychotherapy, so people aren't generally here for major life problems. Sometimes we discover them, and need to refer people.
>
> We have quite a bit of counseling training, but we're not therapists. Long-term therapy is not always in our skill set.
>
> I think for me, then also recognizing the boundary. So if their marriage isn't working, I'm not going to fix their marriage. But if we need to make a decision about X what aspects of this difficult relationship do we temporarily figure out for the next 45 minutes
>
> I think from the psychosocial standpoint, recognizing those issues have an impact on what you're trying to accomplish, but [not] being psychosocial for the sake of being psychosocial.
>
> The job isn't to dig up everything in their past. The job is to recognize what issues are around this particular interaction we're having and certainly if you recognize something, we can help out or provide a referral. But [not] digging into difficult things for the sake of saying you're doing psychosocial counseling. We don't have to go into the whole sordid history of their marriage, just for the sake of asking about [it]. There's a point where you're prying and just sort of trying to make yourself feel good. Like, "Oh, I got them to cry!" or something.

Domain 14. The Changing Landscape of Genetic Counseling

Throughout the interviews participants offered comments on the evolving nature of the profession, from its beginning to present day and into the future. This investigator did not specifically ask participants about their views of the profession, so this theme may be more idiosyncratic relative to the others. The first two subthemes contain comments made by participants who ranged in their years of genetic counseling experience. The final subtheme represents views of participants with the most experience.

The participants perceived the profession as having come a long way and continuing to evolve. Some were reflective in looking back over long careers that grew with the profession itself. A few talked with enthusiasm about what they see as potential new directions. Most regarded continued adaptation as necessary to the vitality of the profession.

As is true in other health care fields, participant master genetic counselors identified health care economics as currently having a significant impact on the field. Other factors mentioned as influencing the evolution of genetic counseling included profound growth in genetic and biogenetic knowledge, changes in technology, and patients' access to information.

Category 1. Evolution of the Profession (*n=9*)

Participants talked about the growth of their profession. Several mentioned changes due to scientific discoveries in the field and how fast those discoveries are occurring.

> I think of my grandma. In her life, literally, she saw the world go from horse and buggy, beyond the space shuttle to Mars missions. And that's how fast genetics is moving. It wasn't that long [ago] that they weren't even sure how many chromosomes we had, and someday we'll be doing gene therapy.
>
> When I was a student the very first DNA test became available. There was one genetic test to do!
>
> [Some of us] got started in a time when there was very little acknowledgement that there was any genetic disease around. This is another story I like to tell: When I first came here… I was stopped within weeks of my arrival by one of the senior staff people who said he has no idea why the hospital [was moving into genetics work because], "We don't see much genetic disease here." And I'm thinking to myself, "Oh Lord, I just moved my family here!" …

> … [Early on] there was reluctance to have non physician people doing anything with genetics patients. I've seen this remarkable shift [in administrative support] to "Boy we've got to have genetic counseling services here, and why shouldn't we be using counselor types!"

A few participants underscored the need for genetic counseling to continue to evolve as a field, and expressed concern about it doing so.

> I think the landscape of genetics is just changing so much. We need to be able to adapt. I hate to say it, but I think that's one of the downfalls of a lot of people in our profession. They sort of see genetic counseling as a static thing; that it's supposed to be the way that it's always been, and there is no room for changing that. And I think that's a big issue for our profession.

Some participants perceived genetics becoming more integrated into health care and thus necessitating alternative methods of service delivery. One participant commented about the possibility of genetic counselors taking on more of a consultative role for other health care providers in more "routine" cases, while themselves seeing cases that are more difficult.

> It used to be that genetics and genetic counseling were really sort of reserved for people with the very well-defined syndromes in the family. And it's just evolving that genetics is going to become so much more integrated into health care. You look at the number of genetic counselors that we have, and we just can't physically see every person that's out there who's going to need information about genetics. So I think we need to think about how we will address that issue, and alternative methods of service delivery. Do we become more of a consultant to other health care providers in providing information about genetics to patients? And can we be the "experts" and "specialists" in seeing those cases that are very difficult.

Category 2. The Impact of Healthcare Economics (*n*=7)

Some participants talked about the impact of health care economics on genetic counseling.

> There are great pressures on hospitals to make a profit. And genetics is not an area that has traditionally been profitable. I worked in a [particular department] and we were never out of the red. The only thing that saved us was being connected with

> a university genetics laboratory, and that's where we made the money. But now, with so many of the laboratories being separated from the universities, that's [no longer] a revenue stream that connects to our services.
>
> There are going to be companies out there that want to make money, and then you look at physicians and health care providers, and they want to do what's good for patients as well, but money is an issue for them… A lot of genetic counselors don't like to talk about that, but it's important; it's part of the world. People want to make money.
>
> That comes back to another question…and that is, trying to figure out how to be in an environment that [financially] supports us. And that's not always easy.

Some participants expressed concern about the counseling component of genetic counseling being minimized in light of healthcare economics.

> So I think … what they can control is how long our sessions are and how many sessions there are, and people are paying a lot more attention to those kinds of variables. And if you have to pack a lot of information into 30 or 45 minutes, where are you going to cut? You obviously have to explain what the test is about, and those kinds of informational pieces that are necessary, and I think what you lose are all those things underneath.
>
> Some programs have gone to sending out questionnaires to gather the family history information beforehand. But [doing a history in-session] is such a wonderful opportunity for talking through the family history with a client; you get so much from that. That's how you learn which of their stories are meaningful to them and what's motivating them, what their needs or wishes or goals are. [Sadly], to lose that may be the way it is, because everything has to be as time efficient [as possible]. That's what's most valued right now.
>
> I think it is a loss for me. And partly because [the strong counseling component] was one of the things that I loved about the field.

Another participant noted the emotional toll a large volume of patients can bring to genetic counselors.

> As I think about it, sometimes volume itself makes you run ragged and makes you less able. It can wear you out. It takes more of an emotional toll.

Another participant noted the impact on patient care.

> In some cases in some settings [they] don't allow you the time you need to take with patients.

Another distinguished the importance of the counseling role as patients continue to gain access to digital information.

> I think with the technology changing with telemedicine and people being able to find stuff on line, what differentiates [genetic counselors] from [anyone] being able to just look something up on the web and find out the information, is really how the information is delivered**.**
>
> I understand that each field is searching to evolve to fit with what's needed at the time, and maybe there are going to be counselors who specialize in the psychosocial part of it.

Another expressed concern that genetic counseling be available to everyone.

> [My concern is] that everyone who needs genetic services gets it.

Category 3. Pioneers' Perceptions (*n=8*)

This subtheme arose from comments made by some of the participants with the most years of genetic counseling experience. They acknowledged the growth in the profession from its inception when many pioneering genetic counselor regarded their career choice as a "calling" to the present when "genetic counselor" is now an established career choice within the allied health professions.

> One of the things that I noticed about those of us who came into the field 20 years ago is that we saw it as a calling. You know it wasn't your average run of the mill career. We really had to sort of find it. And the way that most of us found it was through a personal experience. So it really was a kind of a calling. And that's very different than some of the kids in high school or college who hear about genetic counseling and decide, you know, in a long list of careers, to check this one off.
>
> Some mentioned believing there is a generational difference in views of the profession.
>
> There are generational differences, I think that [genetic counseling students today] are applying to a profession that they see as established, and that's very different than when we were starting.

Participants described themselves and/or other pioneers as “self-starters.”

> If you talk to anyone of the era that I graduated from [many] will have been the first genetic counselor in their city.
>
> I’ve invented [number] of my jobs. Been the first person in almost every job I’ve ever had. Grown clinics from the bottom up, really traditional genetic counseling stuff, and really nontraditional genetic counseling stuff.
>
> Those of us who’ve been around for a long time were pioneers. We went out, and the positions didn’t even exist, and we had to create them. Pretty much everybody who was on the forefront and survived had personalities that facilitated that.

Some also described pioneers as individuals who had social science backgrounds**.**

> Most of us old timers were either social workers, nurses, or had a master’s in public health…

Strong skills in reading people around them were a part of building the profession.

> I think trying to carve out a new profession in [a patriarchal medical] setting took a fair amount of reading the pulse of people around me and then moving forward, and then stopping to let them readjust and then moving forward.

Being an “established profession” offers its own detriments and opportunities.

> I think at this stage in my career probably it’s sad to say, but probably more years behind me than ahead of me, in working in the field. A lot of the people I admire are less experienced than I am.
>
> I don’t see as much of that pioneer spirit any more as the profession is perhaps evolved into adolescence or whatever. I think there’s a little more complacency than what I’d like to see in terms of expectations, in terms of assertiveness, in terms of leadership, in terms of creativity. I see lots of opportunities waiting to happen…
>
> …I think that over the last few years there’s been more and more information about genetics and less and less about interacting with patients. And I’ve personally become very concerned about that because I think you can be a very nice person and be a lousy counselor, and that theoretical underpinnings are very, very important.
>
> New people coming into field “need to know they need work at it; it doesn’t come by osmosis…”
>
> …And we wish we could give [the benefits of founding a profession] to our young students, but we can’t! Because when we started out, we started with 100

> genetic counselors with the National Society of Genetic Counseling, and now there are 3,000! When we started out there was nobody! Nobody knew what it was – still nobody knows what it is, but that's OK … We couldn't measure anything. We couldn't really do much testing, so we really grew up in the field as the field grew. And that's been an amazing experience.
>
> Now what happens, and there's nothing wrong with this, but now what happens is, it's a job like any other allied health professional job that you look up on the internet. You know what I'm saying? So it's listed under audiology, physical therapy, occupational therapy, you know?...
>
> …We've created something that's a regular job and there's nothing wrong with that.

Chapter 5

Discussion

Purpose and Context of the Present Study

In the present investigation distinguished genetic counselors, nominated by their peers, were invited to talk about themselves, share their professional stories, and describe their views of their practice and the profession. This study was designed to begin to describe the characteristics of master genetic counselors--the personal and professional qualities of genetic counselors who might be considered among the best-of-the-best clinicians in their field. Because little is known generally about the professional development of genetic counselors, or what it might take to become a master, this investigation considered the *person* of exemplary genetic counselors.

One broad research question guided the design of this study: *What are the personal characteristics of genetic counselors who are considered among the best-of-the-best by their peers?* Interview questions inquired about their personal qualities and characteristics, inspirations and motivations, strengths and struggles that may have

contributed to their professional development. The question also invited participants' reflection on their professional journey and their perceptions of what it means to be a master genetic counselor. Because the concept of "expert" or "master" genetic counselor had not yet been explored empirically, the present investigation drew upon theoretical frameworks in genetic counseling as well as theory and research in three related helping fields to inform the methodology and interview questions.

Fifteen master genetic counselors participated in a semi-structured, telephone interview. The 16-question interview was modified slightly from landmark studies of master psychotherapists (Jennings & Skovholt, 1999; Skovholt & Jennings, 2004). Interviews were transcribed verbatim by the investigator, and a modified version of Consensual Qualitative Research (CQR; Hill, Thompson & Williams 1997; Hill et al, 2005; Hill, 2012) was used to extract themes, domains, and categories from the data.

This chapter contains a discussion of major findings, their connection to previous research and current theory in genetic counseling, followed by study strengths and limitations, implications for training and practice, and research recommendations.

What are the Characteristics of "Master Genetic Counselors"?

Speaking openly and with passion and commitment, the participating master genetic counselors provided an in-depth look into their perspectives. Results reflect four broad themes: a) Personal Characteristics of Master Genetic Counselors, b) Master Genetic Counselors' Relationship with Patients c) What Constitutes Success in Genetic Counseling, and d) Views of the Profession. The domains and categories—the subthemes—within the broad themes provide insights into genetic counselor professional development.

Summary of Major Findings

Detailed results are presented in Chapter 4. An overview of results is provided in Table **7.** There are 10 major findings:

1. **Master genetic counselors are voracious learners.** They seem to have an insatiable curiosity, a love of learning, and consider themselves to be life-long learners. They are constantly "seeking and searching" and hold a strong passion and "dynamic commitment" to their profession. Master genetic counselors feel honored to learn from their patients.
2. **Master genetic counselors consider their development to be an on-going, career-long process.** Becoming a master genetic counselor requires a certain degree of experience, but the quality of the experience seems to be more important than the quantity. Personal and professional experiences, particularly those involving deep emotions, can influence development. Mentors, colleagues and students play an important role in these experiences.
3. **Master genetic counselors are authentic and genuine. As their professional self matures over time.** With experience, they become increasingly "comfortable in their own skin" and their "personality becomes their style." They find work settings that fit with their personality and counseling style.
4. **Master genetic counselors are reflective, self-aware, confident and recognize their limitations.** They describe reflection as "crucial, dynamic and continuous." Reflection promotes insight and growth, self-awareness, and realistic expectations about one's role and one's impact.

5. **Master genetic counselors form collaborative and interactive relationships with patients.** Master genetic counselors excel in developing safe and trusting relationships with patients. They strive to be "fully present" and engaged and to provide "deep empathic understanding," all of which they perceive as fostering the safety and trust patients need to "open up." They work to equalize the power differential and work collaboratively with their patients.
6. **Master genetic counselors have a nuanced attunement to the complexity and multiple levels of the genetic counseling process.** They are aware of session dynamics, informational and emotional realms (including their own as well as the patients'), patients' cultural and familial contexts, world views, and coping abilities. They are able to "meet patients where they are," which includes tailoring information for a specific patient.
7. **Master genetic counselors have deep empathy, are inspired by their patients, and gain personal meaning from their work.** Master genetic counselors feel deeply inspired by their patients' courage and resilience. They connect with patients on an emotional level, and feel privileged to be able to do so.
8. **Master genetic counselors experience an emotional impact from their work, but they effectively manage it.** Loss, sadness and communicating bad news remain difficult and emotional even for master genetic counselors. They manage the emotional impact by setting boundaries and acknowledging their own limitations.
9. **Challenging sessions for master genetic counselors seem to be those in which they cannot connect with patients.** Master genetic counselors have difficulty

connecting when patients provide little feedback. Angry, aggressive or confrontational patients also can be challenging, although master genetic counselors try to access such patients' underlying emotions.

10. **Master genetic counselors view success in genetic counseling as patient-centered and based in the patient/genetic counselor relationship.** They regard success to be multi-faceted, coming both from the patient's point of view, and grounded in the patient/genetic counselor relationship. They regard trust, relationship, and interactive communication as necessary for information to lead to informed decisions.

Discussion

One decade ago, Abrams and Kessler (2002) offered perhaps the first published look into the "the inner world of the genetic counselor" (p. 11), through vignettes touching on the internal experience of genetic counselors, their "doubts, angst, self-inquiry, and inner strengths" (p. 6). Perhaps, in some small and humble way, through the generosity of the genetic counselors who opened their world to me, our findings add further to that understanding. I believe it is entirely accurate here, to say "our," because my frame is one of trying to tell their stories.

It has been quite an internal struggle at times to make inferences about experts when I am not one, to "tell the story" of people I gained admiration for, and to accurately present people so knowledgeable about the profession. Throughout the interviewing and writing process, I found myself trying to figure out which hat I was wearing--that of journalist, counselor, or researcher. Under each hat I see a different story—or more

accurately, the same story presented in different ways. The characteristics of the participants themselves comprise the major "scientific" findings; they overlap with characteristics of experts in other fields (which supports my sample being experts); and they support the Reciprocal-Engagement Model (REM) of genetic counseling practice (McCarthy Veach, LeRoy, & Bartels, 2007).

But the "real story" is the people themselves and what they do, as well as what the "pioneers" among them did. Which was… "merely" starting a profession from scratch…as women…in a male dominated medical profession. As the upcoming generation might ironically conclude: nbd.

So I switch hats in trying to give voice and honor to what I regard as an ethical responsibility. (And my counselor hat suspects there is some kind of parallel process going on, but perhaps others can see that more clearly than I can at this moment.)

Much of what the master genetic counselors offered, and what emerged as significant in the findings, is their agreement to be interviewed, their openness in talking about themselves, and the self-reflection evident even during a phone conversation with a stranger. They were open, genuine, and authentic in offering verbal access to their thoughts and emotional responses, so that I, too, would have access to them. *Demeanor* is difficult to capture in empirical results, but it is surely part of these findings, and of the story. On the surface of words, we can compile a list of characteristics. But they are just that—words—which cannot capture the essence of the "interaction." The word "interaction" itself, and "empathic engagement" become misnomers, an inadequate attempt to express the "process" that I experienced in talking to these genetic counselors, as they *showed* me how they work.

There was a "dance" that went on in most of the interviews. Often I found myself thinking, "This is how she practices," or "Ahh, he uses that humor with patients." What the genetic counselors revealed about themselves and about how they practice is difficult to sum up in a list of themes, although it *is* there. Describing a felt-sense, even qualitatively, is difficult. And perhaps, it is that felt sense, that is most indicative of "mastery" in genetic counseling—one profound enough to be felt over the phone by a stranger. There is a gift in that, to be sure.

It is also difficult to describe "passion." But that, too, was evident in the interviews. Passion about patients, passion about helping, passion about information and knowledge, passion about the profession, and returning again to, passion about patients. When they talked about their love of on-going knowledge, I pictured kids in a candy store. This passion is what mentors nurtured and reinforced for these master genetic counselors, I suspect. These are, indeed, smart individuals. They love that they "get" to absorb cutting edge research in a cutting edge field. Discovery thrills them. And now they pass on to their students, what one called "infectious excitement." And they can spot those students who "get it" as they did, the next generation of potential master genetic counselors.

It is a drawing in, a sharing of a deep combination of intellectual acumen, relational ease, empathy, honest caring, and emotional connection, and then bringing it back full circle to translating intellectual acumen into an understanding, while facilitating meaning. For some reason, the picture my mind draws is from the *Jetson's* cartoon. I see the genetic counselor in a little, one-person space-age pod, invited in and cruising around inside the much larger cartoon patient, visiting the various parts of who they are, which

are not adequately described by the words of disease, information, family, culture, "psychosocial," importance, meaning, ways of thinking and being. Once finding the three-dimensional intersection of all of these spheres, the genetic counselor returns to the chair opposite, full bodied, understanding a way of relating to *this person* with *these needs* at the intersection of who they are and what they are dealing with at that moment.

While connecting as human-to-human they seem to "internally multi-task,"—being able to simultaneously hold the relationship, information, translation, purpose of session, patient emotions, motivation and meaning, their own emotions, motivation and meaning, while easily and flexibly going where the patient needs to go. They use what they know to help patients discover what they –the patient—knows. They facilitate patient decisions, based on patient needs, wants, desires, emotions and meanings. *That* is what these master genetic counselors consider success in their work. These are necessary outcomes that cannot be realized without the relationship.

Most times it works--and sometimes it doesn't. Of that, they are aware. And while they take it to heart (and, given the opportunity will process interactions that occurred years ago), they mostly accept that they can only do what they can do. Although they truly want to help in the *deepest* way, and they know they can do so, but only if the patient will let them. But patients do not always let them, as these masters have learned though experience. In the past they might have taken it more personally than they do now. But still, those are their most difficult cases. Those in which try as they might, they can't get their *Jetson* bubble into the inner world of the person sitting with them. They try here and there, at different entry points, but sometimes the patient's surface is too rigid, or the patient is too scared, or angry, or hurt to allow connection.

Sometimes the genetic counselor is swatted away. Sometimes patients sit stone-faced and closed off, giving counselors nothing to work with, for whatever personal reasons. Master genetic counselors find it very difficult to meet patients where they are when the patient withholds that location. Thus, it is the cases in which, for some reason, they are unable to create a connection, that are most challenging. They have learned that hurt or fear often underlies anger, and sometimes they can reach that deeper patient emotion. Other times not, and they reflect on it, learn from it, and concentrate on those they can help.

One might think it's the emotionally wrought, tragic journeys they walk with patients that would be the most difficult. Yet, those are the *reason* they are there. That's where they find their awe and inspiration, honor and privilege—their *meaning* in making a horrible situation maybe just a little bit better because they are there to understand, listen, and help. And if the patient thinks the counselor has helped, if they have created a safe and trusting enough relationship that helps meet the patient's needs, that then equals success.

The present findings reflect previous research on genetic counselor development (e.g., Runyon, Zahm, McCarthy Veach, MacFarlane, & LeRoy, 2009; Zahm, 2009) as discussed later in this chapter. Many of the characteristics Abrams and Kessler (2002) described in their essay arose in the present study as well: A sense of feeling complete and whole in the work; expecting and reacting to the unexpected; "when to cry with a client and when to hold back" (p. 14); balance between work and home; a sense of purpose and fulfillment; acknowledgement of limitations; a "sense of solidity," and "the preciousness of the counseling itself" (p.15).

Common Characteristics with Experts in Related Professions

Results of this study indicate that master genetic counselors share many of the characteristics and qualities found in research on experts in related helping and medical fields such as psychotherapy, social work, physical therapy and nursing. Table 8 compares findings about the present sample of master genetic counselors with similar findings in those fields. For example, based on the brief review presented in Chapter 2, master practitioners in psychotherapy, social work, nursing, physical therapy, and genetic counseling share a holistic comprehension of complexity, can prioritize salient issues, are flexible and creative, and easily adapt to changing situations. They also seem to have an intuitive and internal or personalized working style, and confidence in their own professional judgment.

Of particular note, and also consistent with the Reciprocal-Engagement Model (McCarthy Veach, Bartels, LeRoy, 2007) of genetic counseling practice discussed next, is the saliency of relationships with patients/clients. Research in the four professions indicates that ability to create strong patient relationships is a key characteristic of master practitioners. The present findings concur with previous results. Commonalities of expertise across professions include an ability to establish collaborative relationships in which exemplary practitioners view patients holistically and appreciate the contexts of the patients' lives. Additionally, an emotional connection and deep caring and commitment seem to be a characteristic of master practitioners across professions.

Several notes of caution are important in this cross-profession comparison, however, as the literature included in the review for the present study (see Chapter 2) was narrowly defined.

Table 8. Comparison of Master Genetic Counseling Participants' Characteristics With Those Of Master Practitioners In Other Fields

Themes in Other Fields[a]	Related Themes in Genetic Counselor Sample
Holistic comprehension of complexity (4)	• Nuanced attunement to the complexity and multiple levels of the genetic counseling process • Aware of session dynamics
Perceives, understands, and prioritize salient issues (4)	• Tailor salient information • Connecting "science to the individual"
Grasp patterns (4)	
Flexibility, creativity and/or easily adapts to complex and continually changing situations (4)	• Nuanced attunement to the complexity and multiple levels of the genetic counseling process • Flexible and "meet clients where they are" • Aware of session dynamics
Intuitive, internal, and/or personalized working style (4)	• Their personality *is* their counseling style • Use of self: genuine, authentic, and "comfortable in their own skin"
Confident in and/or trust own professional judgment (4)	• Use of self: genuine, authentic, and "comfortable in their own skin" • Confidence
Personal life influences work (1)	• Merging of the personal and professional selves

Saliency of the relationship and/or patient/client-centered (4)	• Collaborative and interactive relationship with patients • Rapport is "crucial"
Collaborative (4)	• Interactive/engagement
Seeks to know the patient as a person and/or understand the context of their life (4)	• Collaborative and interactive relationship with patients • Aware of the power differential • Flexible and "meet clients where they are"
Emotional connection and/or caring; committed to patient/client (4)	• Fully present and empathically involved • Empathic engagement
Excellent interpersonal skills (3)	• Aware of session dynamics • Flexible and "meet clients where they are" • Connection and attunement
Excellent process skills (3)	• Managing challenging and difficult cases, angry patients, etc.
Superior clinical skills (3)	
Extensive experience is necessary but not sufficient for expertise (3)	• Experience required • Quality of experience trumps quantity • Sense of professional self matures over time
A deep knowledge base	• Inspired by science, learning and

and understanding of their specialty area. (3)	new information
Commitment to professional growth or on-going learning (2)	
Learns from clients (2)	• Learning from the families
Reflective practice (3)	• Self-reflection is crucial, dynamic, and continuous • Self-aware: a dynamic process
Self-aware and/or aware of own strengths and challenges (2)	• Realistic expectations and awareness of their limitations
Attend to own emotional aspects of the work and/or able to "let go" (2)	• Loss, sadness, helplessness, and communicating bad news
Importance of healthy balance (competent but realistic; boundaries) (1)	• Emotional Boundaries • Separation of Personal and Professional Lives • Additional Coping/Self-Care Strategies
Humbled to help (1)	• Deep personal meaning from their work
Tolerate ambiguity (1)	• Success can be ambiguous
Optimistic (1)	• Deep personal meaning from their work • Patients' resilience

Mentoring, sense of generativity and/or leading (3)	• "Infectious excitement": the impact of mentoring
Attuned to work setting dynamics (2)	
Skilled at finding resources (1)	

Note: [a]The "other" fields included in this table are: psychotherapy, social work, nursing and physical therapy. Numbers in parentheses indicate the number of other fields that endorsed that theme.

This table includes results from published studies or comprehensive literature reviews specifically focused on aspects of master practitioners. It presents the same studies as included in Table 2**,** but is now organized thematically. The same limitations as previously mentioned apply.

It is entirely possible that the review excluded significant research on professional development in other professions. Further, many of the studies in related professions had a research goal of comparing practitioners' qualities to stages of the Dreyfus model of professional development (Dreyfus & Dreyfus, 1986), and thus were likely narrowly focused. Additionally, Jennings and Skovholt (2004) have cautioned that the characteristic findings in their research may be tapping not master qualities per se, but some other variable such as characteristics resulting from "optimal human development" (Jennings & Skovholt, 1999). That caution would hold true for this investigation as well.

On the other hand, many of the findings in the related professions are compatible with the Dreyfus Model, and the results of this preliminary investigation of master genetic counselors dovetail with those findings; thus they lend support to the idea that this investigation has, indeed, tapped experts in genetic counseling, despite limitations in

the sampling method (see Study Limitations section in this chapter). Extrapolation of these findings to all master genetic counselors or to those in other professions is beyond the scope of this qualitative study.

Support for the Reciprocal-Engagement Model of Genetic Counseling

The present findings strongly support the REM (McCarthy Veach et al., 2007). This support is particularly noteworthy because the interviews were based on questions borrowed from psychotherapy research (Jennings & Skovholt, 1999) unrelated to the REM. Master genetic counselors seem to concur with the beliefs underlying the Reciprocal-Engagement Model, as shown in Table 9. The following section will consider the present findings in the context of the five REM tenets (fundamental principles).

***REM Tenet: Genetic information is key*.** The first REM tenet holds that genetic information is key. Underlying this tenet is recognition that knowledge is power, that knowledge cuts across emotional, cognitive and behavioral realms, that patients desire genetic information, and that genetic counselors know what information is important (McCarthy Veach et al., 2007). As seen in the present findings, master genetic counselors espouse the importance of genetic knowledge. In fact, the science of genetics and learning new information is one of two primary motivations/inspirations for master genetic counselors (the other being patients). They describe their thirst for information and knowledge as both integral and inspirational.

Although the REM tenet is understood in the context of information for patients, it also applies when considering the person of the master genetic counselor. Master genetic counselors are extremely intelligent, and motivated by their *drive* to learn. These

are not people who sit still and react; rather they are active learners with strong curiosity and a love of learning.

Master genetic counselors enjoy the intellectual stimulation of information, and often they seek out knowledge beyond their particular specialty area. In their practice, they are able to sift out that which is salient for specific patients, and they are able to *translate* that information in a way that it becomes meaningful to the patient. Rather than *quantity* of genetic information, which indeed they have amassed, it may be this *refined tailoring* for the patient that sets master genetic counselors apart. Information for the sake of information results in "dumping," while nuanced information leads to patients' informed decisions. Genetic information is key, master counselors agree, but successful genetic counseling depends on facilitating the patients' sense of that information.

Presenting what is salient to the patient, in a way the patient can understand and integrate requires nuanced attunement to the complexity of the patients' world and of the patient/counselor interaction. Combining considerable knowledge with this nuanced attunement and sifting and translation of salient information are qualities possessed by master genetic counselors.

REM Tenet: Relationship is integral. Master genetic counselors embody this tenet which forms the heart of the Reciprocal-Engagement Model of Genetic Counseling. Findings regarding the significance of the counseling relationship for master genetic counselors were particularly prevalent. In fact, the master genetic counselors seem to consider relationship variables to be *defining* characteristic of master genetic counselors. They identified these defining characteristics as the relationships they develop, their empathic engagement, their understanding and attunement to the complex *process* and

multiple levels of genetic counseling, individualized approach, and understanding the patient from a holistic perspective. Further, these master genetic counselors consider the relationship as key to successful genetic counseling.

Thus, master genetic counselors would seem to agree with this REM tenet which maintains the centrality of relationship, connection and communication within genetic counseling. This tenet reflects a fundamental belief that patients need a connection in times of distress; and that patients' familial and cultural relationships are crucial to who they are, how they cope and the decisions they make.

Additionally, master genetic counselors value their relationships with colleagues and mentors. The relational orientation may have deep roots for master genetic counselors. Family of origin experiences and family values played a role in their professional development for at least some participants. There is evidence in the findings that some master genetic counselors grew up with strong family values around caring for others and doing good within their community. Some were taught to respect others, that all human beings have value, and that "some human beings do not have more value than other human beings." Some learned caring from their mothers who took care of ailing family members. Others took to heart early learning that there are two things which can't be taken away from you--your education and your ability to be a good person regardless of your circumstances. Whether characterized as "terribly neurotic," "caring for others," or "no meaning in the word 'stranger'," early family life provided a "training ground" for some master genetic counselors. Childhood families also instilled in some a work ethic or pride in vocation, and the value of intellectual curiosity. This combination of family values resonates with much in the profession of genetic counseling. It also

underscores previous research about the influence of values in genetic counseling, particularly benevolence, self-direction, achievement and universalism (Pirzadeh, McCarthy Veach, Kao, & LeRoy, 2007).

Authenticity and congruence: the building blocks of relationship. The importance of relationship to master genetic counselors cannot be understated, and it may well be master genetic counselors' personal characteristics that allow them to form the necessary rapport for successful genetic counseling.

The relational qualities and characteristics that master genetic counselors possess comprise some of the most compelling findings of the present investigation. Similar to findings about master practitioners in psychotherapy (Jennings & Skovholt, 1999), master genetic counselors are authentic and genuine, reflective, self-aware, confident and aware of their limitations. These personal characteristics and the importance of a collaborative relationship are quite inter-related, and reflect the "common factors" identified in research on the psychotherapy relationship (cf. Norcross, 2010).

It is not surprising that master genetic counselors adhere to the relational qualities of authenticity and congruence, given the professions' foundational genesis from Carl Rogers' (Rogers, 1957) Person-Centered theory. Being authentic, or congruent, means the master genetic counselor "is freely and deeply himself, with his experience accurately represented by his awareness of himself" (Rogers, 1957, p. 97, as cited in Elliott, Bohart, Watson & Greenberg, 2011). Or, as one participant more colloquially put it, "You is what you is, and you ain't what you ain't." As such, master genetic counselors have grown comfortable in their own skin. The master genetic counselor that a patient meets is who that genetic counselor is. Their personality *is* their counseling style; who they are

as a person is evident in their interactions with clients. For the master genetic counselors in this investigation, this seems true whether they describe themselves as warm and a toucher, or as scientifically-minded and more cognitively focused. Thus, it seems there is not one type or style of master genetic counselor, but rather multiple flavors, with the importance being that they are themselves in session, interacting with patients in a genuine and congruent way.

Authenticity and congruence do not seem to occur through osmosis, however, but though the master genetic counselors' dynamic and continuous reflection process. Master genetic counselors continually reflect on themselves, their patients, their relationships with their patients, their missteps, mistakes, misunderstandings, and successes.

For master genetic counselors reflection has become internalized and consistent. It is a common component of their work. Some now find that they are able to actively reflect *during sessions* as their interaction with patients is occurring, and thus they are able to modulate their presentation and conversation to meet a patient's needs in the moment. This seems to be part of their comprehension of the "complexity" and "multiple layers" of the genetic counseling session.

Master genetic counselors are able to monitor multiple phenomena: the information and the person realms, the emotional, cognitive and behavioral realms, the contexts of the patient's external world, and their own present experience of the patient and of themselves, their background knowledge, information and biases, the pieces of information that might be salient for the patient, the patient's readiness to hear the information, as well as decisions that need to be made, and the potential impact of

decisions down the road. When master practitioners in a field known for its "tongue-in-cheek OCD," and not so tongue-in-cheek "perfectionism" or attention to detail, speak of their own defining characteristics such as "flexibility" or "openness," they may be referring to this nuanced ability to move within the complexity and layers. Because they know *who* they are and hold confidence in their ability, and reflect on their experiences, they are able to use "their self"—their own personal qualities and traits-- effectively in sessions.

This level of intra- and inter-personal expertise may grow via developmental processes that are also relationally-based. The process seems influenced to some extent by family of origin values around helping others and intellectual pursuits, but more importantly through the "infectious excitement" of mentors, and later students and colleagues. Master genetic counselors are very relationally-based.

Reflection. Master genetic counselors consider reflection crucial to their development. And as may be true for much of what they do, reflection is not necessarily "merely thinking," but an active and dynamic process of self-analysis and process analysis. Through reflection, master genetic counselors gain self-awareness and insight. Their mental "do-overs" promote development and growth that, perhaps, coalesce in genuineness and authenticity.

Combined with quality experiences over the course of their professional life, reflection leads to a sense of realistic expectations and awareness of one's limitations. Reflection allows them to gain perspective about what they can and cannot achieve on a daily basis, in terms of the impact they may want to make but do not, in terms of good

counseling despite a negative outcome, and in terms of their actual importance in the total scheme of a patient's life course.

Thus, it seems clear that counselor characteristics combined with experience and on-going reflection can lead to master genetic counselors' authenticity and genuineness in the genetic counseling process. Grounded in solid genetic knowledge, self-awareness, confidence and reflective practice, master genetic counselors develop an effective counseling style that builds on and fits with their individual personality and strengths. Their individual counseling styles are authentic and grounded in their individual personalities.

Authenticity, genuineness, and *transparency* (Elliott, Bohart, Watson & Greenberg, 2011) in turn, allow them to create a safe space and the basis for the trust clients place in them. Knowing who they are as people and as genetic counselors allows them to create the trusting connection on which master genetic counselors build the collaborative and interactive relationship which they consider essential for successful genetic counseling. Master genetic counselors' consider their transparency and openness as helpful in developing rapport, and it may be their "human-to-human" contact that differentiates them from other counselors. This intimate connection encourages a strong genetic counselor/patient alliance, facilitates communication, and provides a safe space for clients to open up emotionally. Stemming from deep values of respect, master genetic counselors seem to connect with patients in a deeply empathic manner. This genuineness may be the quality that allows patients to show their own genuine selves, and the pain that may come with it at that moment. And also the coping and survival later. The trust—that goes both ways.

Relationship is reflected through master genetic counselors' professional development, their interactions with each other, and most importantly their interactions with patients. In every participant's comments, the importance of relationship arose repeatedly. They talked about their relationship to the patients, of course, but also relationships to students, mentors and colleagues.

REM Tenet: Patient autonomy must be supported. Master genetic counselors concur with this tenet in many ways. They support the belief of a collaborative and interactive relationship and of collaborative goal-setting. Their focus on mutual goal-setting was evident in the interviews as they assessed this investigator's goals for the interview, even after I had specified them. They are keenly aware of and work to equalize the power differential and consider the patient to be expert on themselves.

Master genetic counselors' awareness of the complexity within the session, and awareness of session dynamics allow for meeting the patient where they are, tailoring information to a specific patient, which also supports autonomy, as does viewing the patient holistically which includes cultural and familial considerations. Flexibility within the complexity allows master genetic counselors to meet patients where they are and to work from a position that is most comfortable for the patient. In the eyes of master genetic counselors, success comes from the patients' point of view.

Master genetic counselors' self-awareness and attention to their own self-care also contributes to patient autonomy. Within any interaction, both parties bring their histories along with them. In being aware of who they are and what they bring to the session, master genetic counselors recognize countertransference and manage it order to focus on the patient. Additionally, through adequate self-care, master genetic counselors are able

to manage their own emotional stress which allows them to be more fully present for the patient.

REM Tenet: Patients are resilient. Master genetic counselors echo this belief in the stories they tell about their patients. The tenet recognizes patients' strengths, adaptations and empowerment, and espouses a belief that with appropriate support patients can handle their difficult situations (McCarthy Veach et al., 2007). Master genetic counselors are deeply respectful of their patients and of patients' resilience, courage, and dignity. In fact, they are *inspired* by the resilience they see in their patients. Many talked of experiencing tragedy with patients, but also the reward they experience in seeing patients "survive and thrive." For master genetic counselors, success includes empowering patients and building their efficacy and competence. They do so through deep empathic understanding, and facilitating patient insight, perspective, understanding and meaning.

REM Tenet: Patient emotions make a difference. Perhaps a more appropriate statement would be "Patients emotions make an impact," because clearly they do, for themselves and for master genetic counselors. Patient emotions interact with all aspects of genetic counseling (McCarthy Veach et al., 2007), and for master genetic counselors this point cannot be understated. Patients' emotions influence everything in the genetic encounter from rapport building to successful counseling outcomes. Emotions affect the relationship, integration of information, decisions and coping. Patients' emotions are often at the heart of challenging cases, and likely near the heart of compassion fatigue as well (cf. Udipi, McCarthy Veach, Kao, & LeRoy, 2008).

Master genetic counselors engage with clients on an emotional level, and consequently gain deep personal meaning from their work. They are *inspired* by their patients, express awe at what their patients experience and contend with, and they marvel at the resilience and courage of the human spirit. Patient resilience gives them perspective on their own lives.

For master genetic counselors, bringing their authentic and genuine self into session means *feeling* and *holding* the patients' emotions. All of the master genetic counselors talked about holding patient's tragedy or trauma close. They described feeling honored when patients trust them to do so. These experiences, too, count as success. Master genetic counselors talked about having created a space in which a patient feels safe and supported enough to touch the deepest fears and sadness of matters that change their lives in ways they had never expected or had desperately hoped against.

These are the stories the master genetic counselors told when given a chance to do so in the interviews. In some ways, it felt as if they were "giving voice" to their patients, and in other ways, the counselors seemed to use the interview as an opportunity to reflect and process further. Clearly patient emotions affect master genetic counselors in profound ways. And they *inspire* them—deeply inspire them—and instill for genetic counselors deep personal meaning from their work.

Despite their capacity to hold patients' emotions, and for their patients to affect them personally, master genetic counselors are able to recognize what is theirs, and what is their patients'. Through reflection, they gain self-awareness and insight, and perhaps this is what enables them to manage the emotional impact from their work. Many talked about "compartmentalization" and "work is work and home is home." A solid sense of

grounding (in who they are) allows master genetic counselors to understand their role in a patient's life, and the patient's role in their own life. They can hold patient's issues without becoming overwhelmed and without unduly "taking it home" with them.

The master genetic counselors in the current study were aware of and monitored themselves for compassion fatigue, but they did not seem to have experienced it. Perhaps their admiration of their patients' abilities to thrive despite obstacles, and their own confidence in their ability to help, stem from traits of optimism, which have been shown to provide a defense against compassion fatigue (Injeyan et al., 2001). Further, it is possible that master genetic counselors' sense of their own limitations, their understanding that there will be patients whom, for whatever reason, they are unable to help, and their realistic expectations about patient outcomes, decrease feelings of helplessness and serve as buffers for compassion fatigue. Finally, master genetic counselors use effective coping strategies for managing emotional distress (Injeyan et al., 2001). For instance, they practice reflection as a matter of course, enjoy strong relationships with colleagues which provide an opportunity for seeking support, and they believe in patients' resiliency.

Master genetic counselors consider their own life experiences to have played a role developing empathy. In addition to the influence of family discussed previously, they noted that life experiences such as living in a different culture or experiencing "life's knocks," enriches a person. They mentioned experiences which give insight into other people's worlds and losses as especially salient in helping to develop the empathy necessary to be a master genetic counselor.

Additional research to investigate the perceived influences of personal life experiences is warranted.

Support for Investigations of Genetic Counselor Professional Development

The present findings overlap with recent research on genetic counselor professional development. For example, findings regarding what genetic counselors learn on the job (Runyon, Zahm, McCarthy Veach, MacFarlane, & LeRoy, 2010) involved several of the topics discussed by the present sample of master genetic counselors. These included: development of self-efficacy, confidence, and self-awareness; letting go of control and acceptance of limitations; flexibility; synergy between personal and professional life and the importance of self-care, work/life balance and boundaries; the importance of a focus on patient interaction; and counselor empathy.

Table 9. Comparison of Master Genetic Counselors' Characteristics to Tenets of Reciprocal-Engagement Model of Genetic Counseling Practice

REM Tenet	Related Master Genetic Counselors Characteristics
Genetic Information is Key	• Insatiable curiosity, love of learning, life-long learning • Inspired by science, learning and new information • Constantly "seeking and searching" • Connect "science to the individual" • Success = Patients integrating knowledge • Success= Information leads to informed decisions

Relationship is Integral	• Create collaborative and interactive relationships with patients • Nuanced attunement to the complexity and multiple levels of the genetic counseling process • Multicultural awareness • Rapport is “crucial” • The pedigree: “the ultimate rapport building tool” • Aware of session dynamics • Fully present and empathically involved • Verbalize intuition and encouraging feedback • Deep empathic understanding • Gain deep personal meaning from the work • Compassion and “dynamic commitment” • Genuine, authentic, and “comfortable in their own skin” • Their personality is their style • Challenging cases = “Button pushers” • Challenging cases = chaotic sessions • Challenging cases = unresponsiveness • Success = Trust and relationship • Success = Interactive communication

Patient Autonomy Must Be Supported	• Collaborative and interactive relationship with patients • Nuanced attunement to the complexity and multiple levels of the genetic counseling process • Success is from the patient's point of view • Multicultural awareness • Flexible and "meet clients where they are" Equalize the power differential • Foster empowerment, efficacy, and competence • Tailor salient information for individual patients • Verbalizing intuition and encouraging feedback • Realistic expectations and awareness of their own limitations • Success = Patients gain insight, perspective, understanding or find meaning. • Success = Multifaceted
Patients Are Resilient	• Inspiration = Patients resilience and courage • Foster empowerment, efficacy, and competence • Flexible and "meet clients where they are" • Deep empathic understanding • Realistic expectations and awareness of limitations • Success = Providing support and facilitating

	coping • Success = Patients gain insight, perspective, understanding or find meaning.
Patient Emotions Make A Difference	• Fully present and empathically involved • Deep empathic understanding • Deep personal meaning from the work • Loss, sadness, helplessness, and communicating bad news • Challenging cases = Angry, aggressive, or confrontational patients/families • Challenging cases = Patients' strong reactions to bad or ambiguous news • Challenging cases = "Button-pushers" • Managing the impact on their own emotions: emotional boundaries and compartmentalizing • Success = Providing support and facilitating coping • Success = Trust and relationship • Success = Interactive communication

Note. [a]Reciprocal Engagement Model (REM) of Genetic Counseling Practice (McCarthy Veach, et al. 2007)

The present results also overlap with findings of a previous, unpublished study which included a group of "seasoned" genetic counselors (defined as having $\geq$ 15 years of genetic counseling experience) (Zahm, 2009). As with the present investigation, that group of "seasoned" genetic counselors had a mean of approximately 23 years of experience (although the range of years for the present sample was much wider). The results of this investigation support Zahm's (2009) conclusions that: seasoned genetic counselors' views of helping become more realistic and less idealistic over time, they view reflective practice as important, and they become more focused on the individual needs of each patient. Zahm further concludes that accumulated experience leads to depth of understanding in more seasoned genetic counselors, and they integrate themselves and their personality into their style of work.

Study Strengths and Limitations

A significant strength of this study is its contribution to a small body of knowledge about the professional development of genetic counselors. In particular, this is the first study to focus specifically on characteristics of counselors who are regarded by their colleagues as having achieved exemplary development. A cross-disciplinary approach allowed for theoretical grounding from research in related disciplines, most specifically psychotherapy (Jennings & Skovholt, 1999).

Additionally, consideration of research on expert development in nursing, social work and physical therapy provided a template for analyzing the current results. Congruence of the present findings with those in other fields provides some comparative

assurance that the genetic counselors in this investigation were, indeed, experts in their field.

Telephone, as opposed to face-to-face interviews, allowed for a national sample. Hill et al. (2005) contend that telephone interviewing is an adequate method of data collection for the CQR method, and in fact, may allow for more open disclosure by participants who may feel less need to present socially desirable responses. This method was effective, in that the interviews generated rich narratives and seemingly candid emotional expression, and they provided a strong sense of each participant's personality. Additionally, interview questions were scripted and all interviews were conducted by the same investigator allowing for consistency in cross-interview comparisons.

This investigator personally transcribed all of the tapes, and then participated in the analysis, providing extensive immersion in the data. The investigator is a skilled interviewer with experience in gathering data as a researcher, a counselor, and as a journalist.

Finally, the participants comprise a significant strength of this study by sharing their experiences, stories, struggles and strengths so openly. They came from across North America, and had graduated from a range of training programs, thus insuring that their voices reflect some variety of training experience. Although the sample was primarily female and Caucasian (which is representative of the profession), it did include some multicultural and gender diversity.

The present study also has several limitations. First, as with all qualitative research, the findings represent a description of a limited number of situations and they are not intended to be generalized beyond the context of the present group, as the

sampling method is intended only to provide information rich cases (Patton, 1990). Qualitative research can be "vulnerable to bias through the attitudes and qualities of the researcher, and social desirability factors" (Hewitt 2007, p. 1149). It is possible that results from the proposed study are idiosyncratic to this sample and/or to the type of genetic counseling settings represented.

Of greater concern, however, is the decidedly low response rate in the two-step nomination process. Of emails sent to 54 leaders in the field requesting nominations for the study, only 6 leaders responded. Consequently the entire participant pool was nominated by just six people. This small response likely limited the pool of possible participants considerably. Additionally, no participant was nominated by more than one leader.

This limitation raises a question of relationships between nominators and those nominated, as well as why such a low response rate from nominators. Perhaps people were unsure of who might be a "master genetic counselor," or the definition of the concept itself. Although a definition was provided in the email, it is possible that nominators did not take the time to read it. Further, the description included an attachment, which some may have been hesitant to open as it came from someone they did not know. It is also possible that clinicians were hesitant to put forth the names of genetic counselors they suspect are excellent clinicians, but whom they have never had the opportunity to see practice. Further, it was assumed that "leaders" in the field of genetic counseling have knowledge of genetic counselors who are exemplary clinicians.

Although the sample was geographically dispersed, no one was from the southeastern part of the U.S. This is interesting because that part of the country includes

several areas of the highest concentrations of genetic counselors in the U.S. Further, there may be some sample bias toward those individuals who are active in professional organizations or whose names are familiar is possible.

Another limitation is the data are based solely on self-report and therefore carry personal bias. Also, the findings do not provide insight into what *patients* regard as the characteristics of master genetic counselors. Questions were emailed to participants once they had scheduled an interview to provide an opportunity for reflection on the questions and their responses. However, participants varied in the degree to which they reviewed the questions prior to the interviews, with some noting they had written down responses to which they referred as we talked, while others noted they had not reviewed the questions at all. A few participants commented on some redundancy in the questions, as well as some of the limitations of the study.

The method of analysis also has some limitations. Consensus in CQR research can be affected by the cultural make up and context of the research group (Stiles, 1997), as well as group dynamics (Hill et al., 1997), and the schedules and experience of the team members. All of the individuals involved in data analysis/auditing were white and female, although there was some variability in their ages.

Consequently, these limitations should be considered in interpreting the results of this study.

Research Recommendations

This investigation suggests several areas that would expand the knowledge base of genetic counselor development, characteristics of exemplary counselors, and the *process* of genetic counseling. Becoming a master genetic counselor requires a certain

degree of experience, but the *quality* of the experience seems to be more important than the *quantity*. What constitutes "quality" experience? Some master genetic counselors discussed experiences in their families of origin which helped form values they now use in their professional lives. Others noted experiences which develop the capacity for deep empathy. Further research on non-patient related influences on master genetic counselors' development is warranted. Additionally, studies of master genetic counselor empathic characteristics (cf. Elliott, Bohart, Watson, & Greenberg, 2011) could further clarify the role of empathy in genetic counseling, and further illuminate ways in which master genetic counselors manage their emotional connections without experiencing compassion fatigue.

The present findings strongly support a practice model that places paramount importance on the relationship between the genetic counselor and the patient. Since the relationship underlies all else, and figures prominently in successful genetic counseling, additional research is necessary to answer the question of *how* master genetic counselors establish the relationship. How is it, that in a relatively condensed timeframe, they are able to connect in a way that benefits patients by providing them a safe space and an opportunity to touch their deep emotions? What strategies and specific behaviors enhance or detract from establishing the necessary relationship? Further delineating how master genetic counselors practice would enable novice genetic counselors and others who want to refine skills to focus on particular behaviors that enhance their skills.

The blend of empathic ability and scientific learning and knowledge embodied by master genetic counselors is also interesting. Process studies could determine how and when they maneuver between these areas. Interpersonal process recall studies in which

master therapists discuss what they were thinking and feeling while viewing a videotape of a previous genetic counseling session would yield further insight into their "inner world." Such studies would also identify advance counseling skills used by excellent practitioners.

Although the characteristics of the present sample share considerable overlap with other helping professions, additional research is necessary to further illuminate the characteristic of master genetic counselors. Comparisons across groups of genetic counselors—for example, comparing the characteristics of master clinicians with genetic counseling experts who excel in work other than patient-contact—may reveal different developmental journeys and additional realms of expertise in the profession. Also, investigating similarities and differences between "master genetic counselors" and "leaders in the field" or with peer nominated "local" master practitioners would solidify conclusion derived from the present study.

Further studies can also enhance understanding of counselor development. Some factors of professional development have been identified (e.g., Runyon, et al., 2010) and research has begun on understanding the process of professional development (Zahm, 2009). Further understanding of what *prevents* some people from achieving a "master" level of development would add to this understanding, as well as potentially identify areas of development for training intervention. One of the interview questions in this study inquired about "barriers" to becoming a master genetic counselor. Responses tended to be along the lines of absence of factors the interviewee deemed important (e.g., mentors are helpful, and a barrier would be not having a mentor), so added little to the present discussion.

In responding to interview questions about the psychosocial aspects of genetic counseling and another asking about the extent genetic counseling is an "art" vs. a science, the master genetic counselors in this study revealed a widely debated question within the field. Is there an "art" to genetic counseling, and if so, what does it encompass? This debate seemed centered on advanced counseling skills and whether or not such skills can be "taught" or are based on more innate "emotional intelligence." The question becomes even more interesting considering that much of what master genetic counselors considered characteristic of their work involves the counseling *process.* Thus, further investigation of counseling skills—particularly advanced counseling skills--and the genetic counseling process are quite warranted.

The dichotomy of characteristics necessary to become a master genetic counselor provides a basis for further research on why some counselors develop into master practitioners, while others do not. For example, master genetic counselors possess an intriguing blend of superb intellect and distinguished helping skills such as empathy and positive regard. Master genetic counselors talked of "going above and beyond" and seeing their job as being "more than 9 to 5." At the same time, they managed the emotional impact of their work by balancing and separating work time and home time. How does a genetic counselor become a master while also balancing "passion" with an adequate work/home ratio? Although it would apply to both genders, it remains that work/life balances often falls disproportionately on female workers, which would have an impact in a female-dominated profession. Lastly, studies across developmental levels are necessary in order to further validate the REM.

Training and Practice Implications

This investigation adds additional support to the importance of genetic counselor reflective practice, self-awareness, and self-understanding (e.g., Zahm, 2010). If "personality *is* a genetic counselor's style," the more genetic counselors know about themselves, the more they can develop their unique style, and thus, the more effective they can be with patients. Therefore, promoting genuineness and authenticity becomes an important goal in genetic counselor development.

Personal counseling for professional development is one way to gain self-awareness. Genetic counselors understand from their own work the benefits of exploring one's self with a compassionate other. Opening themselves up in the same way, in an equally safe space and trusting relationship, is an excellent means of developing the self-knowledge necessary for genuiness and authenticity. Enhanced self-understanding and self-awareness enables genetic counselors to recognize countertransference which influences counselor/patient dynamics. Proactive personal counseling can also help prevent compassion fatigue, process stress and trauma, help manage work/life balance, and model advanced empathy counseling skills.

Another way to increase self-understanding is through personality assessments such as the MBTI or similar instruments which identify "ways of being" in the world. Such instruments also provide a detailed, external look at self-in-relationship, which can further develop a genetic counselor's ability to create the trusting, strong genetic counselor/patient relationship, identified in this investigation as underlying the genetic counseling process (Veach et al.,2007; McCarthy Veach et al., 2010). Such assessment can easily be administered and processed in class or continuing education workshops

while maintaining individual privacy, and participants often find it to be an engaging and informative experience.

Growing research is identifying the importance of reflection in genetic counseling, and master genetic counselors are calling it “crucial, dynamic and continuous.” Providing on-going opportunities for reflection during training will build the practice into career-long benefits. Reflective practice can increase self-awareness and understanding, help recognize limitations, provide a means of addressing stress and vicarious trauma, all of which promote master development. It is important for genetic counselors to have ample opportunities to learn *how* to reflect, and to have time to do so within their workday. Clinical supervisors should encourage students to develop an individual style of counseling since findings indicate there is no single "right style" of counseling, and master counselors identify finding comfort with their own style as a pertinent characteristic once they have the science down.

Genetic counselors might benefit from additional training in understanding and coping with intense patient emotions. Prior research evidence indicates that intense patient (and counselor) affect is ethically and professionally challenging for genetic counselors (McCarthy Veach, Bartels, & LeRoy, 2001). Training and workshops might involve helping genetic counseling students understand the role of intense affect such as anger, and strategies for reaching beneath it.

Participants in this study, even at their level of expertise, lamented having no opportunities to observe other counselors in action. Several noted that their students know more about how other genetic counselors practice than they do. Providing a means for such observation would surely promote professional development at all levels.

Additionally, master genetic counselors noted the importance of relationships with their colleagues and the significance of mentors in their development. Even at this juncture in their professional development, some expressed a desire for more opportunities for peer support/supervision. They viewed peer supervision/consultation as a way to develop skills, refine their personal style, practice self-reflection, and learn from other counselors. Further, peer support/supervision groups could provide an outlet for processing vicarious trauma experienced in their work with others who truly understand the variety of emotions attendant to it (Zahm, McCarthy Veach, & LeRoy, 2008).

And finally, I hope genetic counselors and students in training will have the opportunity to interact with the "best of the best" pioneering genetic counselors in the way I did in this study. They have so much to give.

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Appendix A

Portrait of the Master Genetic Counselor: Identifying Expertise in Genetic Counseling

Dear Leader in Genetic Counseling:

Do you know a few practicing geneticcounselors – perhaps unsung heroes – whom you would consider to be among the "bestofthebest"?

For my dissertationresearchattheUniversityofMinnesota, I would like to invitethese exemplary clinicians to participate in a telephone interview. I am writing to askyourhelp as a leader in the field inidentifyingtheseindividuals.

I would ask that you read the invitation below, and then forward it to 3-5 practicinggenetic counselors whom you:

- would offer as a referral to a family member or close friend because you consider her or him to be among the "best of the best" genetic counselor practitioners or
- would have full confidence in seeing for your own genetic counseling or
- consider to be a master genetic counselor

Alternatively, you can reply with your recommendations and I will forward the invitation to them.
Please feel free to contact me with any questions or concerns at mira0026@umn.edu or 612-730-7009.

You are also encouraged to contact my dissertation advisors Pat McCarthy Veach (612-624-3580, veach001@umn.edu) and Bonnie LeRoy (612-624-7193, leroy001@umn.edu).

Thank you very much!

Cacy Miranda, MA

Doctoral candidate in counseling psychology
Department of Educational Psychology
University of Minnesota
mira0026@umn.edu

612-730-7009

Portrait of the Master Genetic Counselor: Identifying Expertise in Genetic Counseling

Dear Genetic Counselor:

You are invited to participate in a research study of the personal characteristics of “master” genetic counselors. To locate possible participants, we asked leaders in the field to help identify practicing genetic counselors whom they regard as among “the best of the best.” Congratulations, they identified you as an exemplary clinician.

We ask that you read the following information and contact us with any questions you may have.

This study is being conducted by Cacy Miranda, MA, doctoral candidate in counseling psychology at the University of Minnesota, Department of Educational Psychology.

The purpose of the study is to begin to describe the personal qualities, characteristics, and behaviors of genetic counselors who have been identified as excelling in their work with clients. Since no research has been done on what it means to be an “expert” or “master” genetic counselor, qualitative research will help lay the groundwork for future research on this topic.

The research question is:

What are the personal characteristics of master genetic counselors?

Relevant background information: Many professions have published literature describing the characteristics of “master” practitioners in their fields. These include mental health counseling, nursing, and other medical disciplines. Understanding the personal qualities, inspirations, strengths, and struggles of people considered to be the “best-of-the-best” within their respective fields can influence best practices, training, professional development, and ultimately the public served.

The concept of “expert” or “master” genetic counselor is, as of yet, unexplored. This study draws upon theoretical frameworks in related fields to inform its methods and specific interview questions.

Ifyouagreetoparticipateinthisstudy,wewouldaskyoutodothefollowing:

- Respond to the Contact Information Form at the end of this email and forward it to Cacy Miranda, mira0026@umn.edu.
- She will contact you to schedule a 30-45 minute interview at a time of your convenience.
- Participate in an in-depth telephone interview about your professional journey, including your motivations and inspirations, professional struggles and successes, as well as your perspective on personal characteristics of master genetic counselors. Interview questions will be standardized and emailed to you in advance.

This is a minimal risk study with the only perceived risk of your participation being possible discomfort with discussing some of your challenges as a genetic counselor.

There are no direct benefits to you for participating in this study.

The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify you as a participant. Research records will be stored securely and only researchers will have access to the records. Telephone interviews will be audiotaped and transcribed. Identifying information will be removed from all transcripts and data will be stored in a password protected computer. All tapes will be destroyed after transcription and no identifiers will be kept.

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

Contacts and Questions:

The researcher conducting this study is Cacy Miranda. If you have questions, you are encouraged to contact her at the 612-730-7009 or mira0026@umn.edu. Cacy holds a master's degree in mental health counseling and has practiced counseling in a number of settings. She is an experienced interviewer and has conducted previous research on the process of genetic counseling, including observing more than a dozen genetic counseling sessions.

Cacy's advisors are Pat McCarthy Veach, who can be reached at 612-624-3580, veach001@umn.edu, and Bonnie LeRoy, who can be reached at 612-624-7193, leroy001@umn.edu.

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

Thank you for your time and consideration.

Sincerely,

Cacy Miranda, MA
Doctoral Candidate
Counseling Program
Educational Psychology

Pat McCarthy Veach, PhD, LP
Professor
Educational Psychology

Bonnie S. LeRoy, MS, CGC
Director, Genetic

Participant's Contact Information Form

I have read the information above and agree to be contacted by Cacy Miranda (mira0026@umn.edu) for participation in a research study investigating the personal characteristics of master genetic counselors.

Forwarding this email to the researcher at mira0026@umn.edu gives consent for the researchers to contact me.

I agree to ask any questions I might have prior to scheduling or participating in an interview.

Name:

Phone number(s):

Email:

Do you prefer being contacted via phone or email?

What are good times to contact you to schedule an interview?

Are you currently seeing patients or have you seen patients in the past two years?

Thank you!

Appendix B

Portrait of the Master Genetic Counselor: Identifying Expertise in Genetic Counseling

Dear :

You are invited to participate in a research study of the personal characteristics of "master genetic counselors" – i.e. clinicians who might be regarded as outstanding among their peers. To locate possible participants, we asked leaders in the field to help identify practicing genetic counselors whom they regard as among "the best of the best."

Congratulations, they identified you as an exemplary clinician!

Therefore, we would like to invite you to participate in the study, which is being conducted as dissertation research by Cacy Miranda, MA. Cacy is a graduate student in counseling psychology at the University of Minnesota's Department of Educational Psychology. Her advisors are Pat McCarthy Veach and Bonnie LeRoy.

We ask that you read the following information and feel free to contact us with any questions you may have. At the end of this email you will find a brief response form for replying.

Thank you!

Cacy Miranda, MA
Doctoral Candidate
Educational Psychology
University of Minnesota

mira0026@umn.edu
612-822-8727
612-730-7009

Pat McCarthy Veach, PhD, LP
Professor
Educational Psychology
University of Minnesota

Bonnie S. LeRoy, MS, CGC
Director, Genetic Counseling Program
University of Minnesota

INFORMATION

Portrait of the Master Genetic Counselor: Identifying Expertise in Genetic Counseling

If you agree to participate in this study, we would ask that you:

- Participate in an in-depth telephone interview about your professional journey, including your motivations and inspirations, professional struggles and successes, as well as your perspective on what makes an exemplary genetic counselor. Interview questions would be standardized and emailed to you in advance.
- Send your contact information (via the "Contact Information Form" at the end of this email) to Cacy Miranda, mira0026@umn.edu, who will then contact you to schedule the interview at your convenience. We expect interviews to take 30-45 minutes.

The purpose of the study is to begin to describe the personal qualities, characteristics, inspirations, strengths, and struggles of genetic counselors who have been identified as excelling in their work with clients. Since no research has been published on what it means to be an "expert" or "master" genetic counselor, qualitative research will help lay the groundwork for future research on this topic.

Our research question is:

What are the personal characteristics of master genetic counselors?

Background information: Many professions have published literature describing the characteristics of "master" practitioners in their fields. These include mental health counseling, teaching, nursing, and other medical disciplines. Understanding the characteristics and behaviors of people considered to be the "best-of-the-best" within their respective fields can influence best practices, training, professional development, and ultimately the public served. The concept of "expert" or "master" genetic counselor is, as of yet, unexplored. This study draws upon theoretical frameworks in related fields to inform its methods and specific interview questions.

Risks, benefits and confidentiality: This is a minimal risk study with the only perceived risk of your participation being possible discomfort in discussing some of your challenges as a genetic counselor.

There are no direct benefits to you for participating in this study.

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

The records of this study will be kept private. Telephone interviews will be audiotaped and transcribed. Research records will be stored securely and only researchers will have access to the records. Identifying information will be removed from all transcripts and data will be stored in a password-protected computer. All tapes will be destroyed after transcription and no identifiers will be kept. In any sort of report we might publish, we will not include any information that will make it possible to identify you as a participant.

Contacts and Questions:

The researcher conducting this study is Cacy Miranda. If you have questions, you are encouraged to contact her at the 612-730-7009 or mira0026@umn.edu.

Cacy holds a master's degree in mental health counseling and has practiced counseling in a number of settings. She is an experienced interviewer and has conducted previous research on the process of genetic counseling, including observing more than a dozen genetic counseling sessions.

Cacy's advisors are Pat McCarthy Veach, who can be reached at 612-624-3580, veach001@umn.edu, and Bonnie LeRoy, who can be reached at 612-624-7193, leroy001@umn.edu.

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

Again, if you would like to participate, please scroll down, fill out the form below this letter, return it to mira0026@umn.edu, and Cacy will contact you.

Thank you for your time and consideration!

Sincerely,

Cacy Miranda, MA

Doctoral Candidate

Educational Psychology

University of Minnesota

Pat McCarthy Veach, PhD, LP

Professor

Educational Psychology

University of Minnesota

Bonnie S. LeRoy, MS, CGC

Director, Genetic Counseling Program

University of Minnesota

Contact Information Form

I have read the information above and agree to be contacted by Cacy Miranda (mira0026@umn.edu) for participation in a research study investigating the personal characteristics of master genetic counselors.

My reply to this email gives consent for the researchers to contact me.

I agree to ask any questions I might have prior to scheduling or participating in an interview.

Name:

Phone number(s):

Email:

Do you prefer being contacted via phone or email?

What are good times to contact you to schedule an interview?

Are you currently seeing patients or have you seen patients in the past two years?

Please return this form to

Cacy Miranda, MA
Doctoral candidate in counseling psychology

Department of Educational Psychology
University of Minnesota
mira0026@umn.edu

Appendix C

Portrait of the Master Genetic Counselor: Identifying Expertise in Genetic Counseling

Participant Demographic Form

1. What is your current age?
2. What is your gender? M F
3. What is your ethnic/racial group?
4. What is your highest level of education? BA/BS MA/MS PhD
5. Where did you graduate from genetic counselor training?
6. How many years of post-certification experience in genetic counseling do you have?
7. In what type of settings have you worked as a genetic counselor? (Please list all post-graduate settings)
8. In what type of setting do you currently work?
9. What percentage of time do you spend in direct service?
10. What are your main areas of practice?
11. Do you work full-time/part-time? FT PT
12. How many clients do you see per day on average?
13. What other aspects of genetic counseling to you participate in? (e.g., teaching, supervision, research, other)
14. Please list any genetic conditions in your family history.
15. Did this influence your decision to become a genetic counselor? How?
16. Is there anything else about your background that we should know?

Thank you!

Appendix D

Portrait of the Master Genetic Counselor: Identifying Expertise in Genetic Counseling

Below are the 16 questions all participants will be asked during their interviews. We are looking for your personal opinions, perspectives, wisdoms and insights. Please feel free to respond as reflectively as you would like. A brief demographic form follows the questions. THANK YOU!

For more information contact Cacy Miranda, MA mira0026@umn.edu

Interview Questions

1. What, in your opinion, distinguishes a great genetic counselor from a good genetic counselor? For example, what does it take to be a good genetic counselor? (e.g., attitudes, skills, values, etc.) What does it take to be *one of the best* genetic counselor?

2. To become a master genetic counselor, does one need years of experience? Explain.

3. In your opinion, what are the necessary attitudes, values or traits of a master genetic counselor?

4. Given equally experienced genetic counselors, what prevents some from becoming master counselors? For example, when you think of all the skills used in genetic counseling, are there certain skills that a master genetic counselor optimizes beyond basic competencies?

5. How much of genetic counseling, would you say, is an art versus a science?

6. How does the person you are impact the genetic counseling you do? For example, how do you think your personal characteristics (e.g., personality traits, temperament, etc.) are reflected in your work with clients?

7. What would someone say "stands out" about your practice/how you practice genetic counseling? For example, are there distinguishing aspects of your expertise? What is it that is particularly effective about how you practice genetic counseling?

8. To what extent has that "distinguishing aspect" always been true of you versus something you have developed over time? If it has developed over time: What do you think contributed to your development of it?

9. Can you take a moment and recall one of your most successful cases? What about it made it successful? *If you can't think of a specific case*, then tell me what generally characterizes your successful sessions.

10. And now if you think of the other end of the spectrum, can you talk about a case that was, perhaps not your "finest moment" as a genetic counselor? What do you think was going on that made it less successful than you would have liked? How did this case affect you at the time?
11. How do you know when you are doing a good job with a client?

12. Are there some clients that you are not as effective with? Explain.

13. How does your work as a genetic counselor affect you personally? What is the emotional impact of genetic counseling on you? How do you manage the emotional intensity of your work? For example, in mental health counseling research has found that the emotional health of a counselor can affect their work with clients. Do you think that's true for genetic counselors? How does your emotional health affect the counseling you do?
14. What inspires you as a genetic counselor?

15. What do you think is meant by the "psychosocial" aspect of genetic counseling? How do you address that in sessions?

16. If there were a recipe for making a master genetic counselor what ingredients would you use?